

California Initiative to Advance  
**Precision Medicine**

# 2020

Annual Report to  
the California Legislature

PREPARED BY THE  
GOVERNOR'S OFFICE OF PLANNING AND RESEARCH

California Initiative to Advance Precision Medicine  
Annual Report to the California Legislature  
Prepared by the Governor's Office of Planning and Research  
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# Contents

<b>Executive Summary</b>	<b>ii</b>
<b>Message from the Director</b>	<b>iv</b>
<b>Background</b>	<b>1</b>
<b>Program Highlights</b>	<b>4</b>
<b>Demonstration Projects</b>	<b>15</b>
<b>Network Engagement</b>	<b>25</b>
<b>Conclusion and Next Steps</b>	<b>28</b>
<b>Appendices</b>	<b>29</b>

# Executive Summary

*California for All*—the State of California’s vision under the Newsom Administration—calls for courageous cross-sector leadership from government, industry, nonprofit, and community-based partners to work together to strive toward equity. That vision became more significant in 2020, a year defined by a pandemic, a national reckoning over racial injustice, and increasing climate-related disasters including devastating wildfires and several months of extreme heat. As part of the greater effort to reduce racial, gender, geographic, and other disparities and carry the state through the pandemic, the California Initiative to Advance Precision Medicine (CIAPM) continued to lead and participate in wide-ranging, cross-agency efforts to further medical sciences, elevate community partnerships, and engage experts in helping to shape the next chapter of health and wellbeing in a modern era of scientific and inclusive leadership. Pursuant to CA Government Code, section 65057(b)(4)(A), CIAPM staff have prepared this report to showcase 2020 programmatic and project highlights, which include the following:

- ▶ Advanced the state’s response to COVID-19 by contributing time and expertise as members of the Governor’s COVID-19 Testing Task Force and the Governor’s Future Opportunities Task Force
- ▶ Established and convened the California Precision Medicine Advisory Council, in coordination with the Senate, Assembly, and California Health and Human Services Agency
- ▶ Launched two Advisory Council working groups focused on 1. integrating data about Social Determinants of Health into electronic health records, and 2. engaging with underrepresented communities to increase participation in biomedical research
- ▶ Co-authored and supported the release of the first-ever report by the Office of the California Surgeon General, *Roadmap for Resilience: The California Surgeon General’s Report on Adverse Childhood Experiences, Toxic Stress, and Health*
- ▶ Added to OPR’s capacity to address systemic racism by participating in the Capitol Collaborative on Race and Equity and continuing to fund research

that directly addressed health disparities

- ▶ Expanded programmatic communications and outreach with a new monthly newsletter and public-facing resources on the OPR website
- ▶ Engaged the wider precision health community by speaking at national and international conferences and participating on panels

Bolstered by years of strategic planning and targeted investment with partners throughout the state, CIAPM positioned itself to support the immediate needs of the state while also looking ahead and building capacity for the future.

Precision medicine has the capacity to revolutionize life sciences, health care delivery, preventive care, and how we harness technologies for equitable outcomes by making sense of the complexities of an ever-changing world. Never before was the need for greater acceleration of the science and implementation of precision medicine science as apparent as during 2020, and California will continue to lead.

# Message from the Director

Members of the Legislature:

On behalf of the Governor's Office of Planning and Research (OPR), I am pleased to present the 2020 *Annual Report for the California Initiative to Advance Precision Medicine* (CIAPM). From its inception as a one-time, \$3 million investment in 2015, CIAPM has grown into a unique and valuable program representing the best of what state government can be—nimble, efficient, and effective. During a year defined by a pandemic, CIAPM rose to the moment and exemplified how public investments in early-stage research can benefit Californians and increase the state's capacity to respond to a public health emergency, while investing in building resilience and innovative solutions to future crises.

CIAPM's statutory requirements include funding and managing precision medicine demonstration projects and creating and maintaining an inventory of California's precision medicine assets. In addition to managing these tasks, CIAPM took an active role to lift up important work of fellow agencies. Helping to make state history, CIAPM co-authored and provided administrative and design support for the first-ever California Surgeon General's Report, titled, *Roadmap for Resilience: The California Surgeon General's Report on Adverse Childhood Experiences, Toxic Stress, and Health*. The partnership between the California Surgeon General and CIAPM continues to strengthen as OPR prepares to award multi-year research projects in early 2021 to address the health impacts of Adverse Childhood Experiences through a precision medicine and community-led approach.

At the start of the pandemic, CIAPM's co-directors, both of whom are biomedical scientists with virology experience, immediately stepped up to serve on the Governor's COVID-19 Testing Task Force alongside OPR's Science & Technology Fellow. Numerous members of the CIAPM network, including previous grantees and current and former advisers, were also integral players in the state's response to the pandemic. The program's early investment in innovative approaches to infectious diseases led to key outcomes during the pandemic: from 2015–2018, CIAPM granted research funds to Dr. Charles Chiu

of UC San Francisco to develop a set of precision diagnostic technologies that, during the pandemic, was one of the state's greatest assets for tracking the spread and mutations of the virus.

CIAPM's work serves as a testament to OPR's commitment to provide strategic support and guidance to the Governor and Cabinet on long-range issues while working across agencies and with outside partners to advance the state's core goals of sustainability, resilience, and equity. As with all OPR programs, CIAPM continues to punch well above its weight.

Thank you for your continued support of this critical work.

Sincerely,

A handwritten signature in black ink, appearing to read "Kate Gordon". The signature is fluid and cursive, with the first name "Kate" being more prominent than the last name "Gordon".

Kate Gordon

Director, Governor's Office of Planning and Research



# Background

## What is Precision Medicine?

Prior to the 21st century, health care practitioners had to practice medicine largely on an analog basis. They collected medical questionnaires and records on paper and stored them in physical folders on office shelves. Transferring medical information between specialists at different facilities required photocopying or faxing documents, which took time in situations that were often urgent. Organizers of clinical trials, especially for rare conditions, could spend years finding, recruiting, and enrolling patients, yet only be able to test a few variables at a time. Emergency room staff had little or no knowledge of patients' medical histories, resulting in misdiagnoses, dangerous drug interactions, and wasted time and resources.

Similarly, physicians prescribed treatments knowing that for many or even most patients, the treatments would be ineffective or induce intolerable side effects, but there was no way to predict how any one patient would respond. Patients' data, such as responsiveness to a new prescription, could only be collected every few weeks, and necessitated a trip to an office or clinic.

Recent advances in computer science, medical imaging, mobile devices, biotechnology, and social science are enabling advances in health once imagined only in science fiction. Physicians can eliminate the need for a patient to visit the clinic by using portable mobile sensors that continually report biometrics to a patient's medi-

cal record. Complex diseases such as cancer have been divided into types and subtypes that are treated with increasingly specialized drugs, and a patient's DNA sequence can be used to predict whether a drug will be well tolerated, or even effective.

Precision medicine approaches aim to use advanced computing tools to aggregate, integrate, and analyze vast amounts of data from research, clinical, environmental, and population health settings, to better understand health and disease, and to develop and deliver more targeted diagnostics, therapeutics, and prevention measures.

The goal is to give the right treatment at the right time to the right person.

In recent decades, the medical community has gradually begun to accept that social factors, including housing and food security, education, and health literacy have a significant—even outsized—effect on medical outcomes. Events of 2020, including the COVID-19 pandemic, brought into the vernacular the concept of precision *public health*, which concerns the use of data and technology to improve public health equity, policy, and



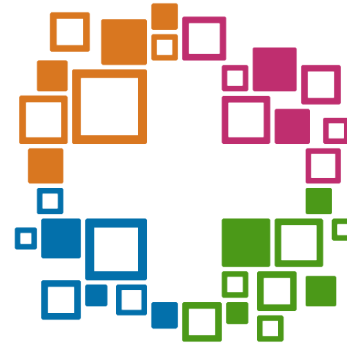
practice. Like precision medicine, precision public health aims to provide the right intervention at the right time to the right population.

Fragmentation is transforming into connectedness. The unsearchable is becoming searchable. The future of precision medicine and precision public health are bright, yet all partners, from government entities to researchers and providers to community leaders, still have much work to do. Important issues of privacy, equity, and financing remain unresolved and solutions lack universal implementation. Public funding for health sciences research will help to ensure that the advances made using a precision medicine approach benefit all of society, not just a select few.

## Brief History of CIAPM and Allocation of Funds

California is home to 10 of the world's top 100 institutions for biomedical sciences, seven of the world's top 100 schools for public health, seven of the world's top 20 digital technology companies, and more than one out of every six medical scientists in the nation. It is also the most diverse state in the nation, which brings with it a responsibility to work with communities that reflect a wide spectrum of cultures, geographies, languages, and income levels, to address complex health needs and reverse historical injustices.<sup>1</sup>

1 <https://www.natureindex.com/supplements/nature-index-2019-biomedical-sciences/tables/overall>; <https://www.usnews.com/education/best-global-universities/social-sciences-public-health>; <https://www.forbes.com/top-digital-companies/list/#tab:rank>; <https://www.bls.gov/oes/current/oes191042.htm#st>



## California Initiative to Advance Precision Medicine

### CIAPM's Establishing Statute

California, with its vast scientific, medical, and technological resources, is positioned to lead advances in the field of precision medicine, which is gaining both national and international prominence. By establishing a **California Initiative to Advance Precision Medicine**, the state can help coordinate public, private, and nonprofit partners to advance this important intersection between science, research, and medicine, and to foster the creation of new technologies and therapies that can improve the health of Californians. A California Initiative to Advance Precision Medicine will bring together state precision medicine leaders as well as complete projects that demonstrate the power and application of precision medicine to the people of the State of California.<sup>2</sup>

2 CA Government Code, section 65055.

Since 2014, the Legislature has appropriated \$53 million to fund precision medicine demonstration projects selected based on criteria including:

- ▶ The potential for tangible benefit to patients within two to five years, including the likelihood that the study will have an immediate impact on patients.
- ▶ The clinical and commercial potential of the project.
- ▶ The potential to reduce health disparities.
- ▶ The potential to develop the use of tools, measurements, and data, including publicly generated and available data.

The State’s investment has also enabled the creation of the California Precision Medicine Asset

Inventory to facilitate collaborations between researchers, clinicians, community groups, and industry partners and highlight databases from the state, federal government, and private entities that enable research studies and analysis.

In the 2018–19 Budget, the Legislature appropriated \$30 million to CIAPM, intended to fund precision medicine demonstration projects across the state. In 2020, the COVID-19 pandemic and resulting strain on state resources required CIAPM to work with the Department of Finance to reallocate \$18.2 million of CIAPM’s 2018–19 funds to cover immediate needs, such as safety-net services like food banks and Medi-Cal for those hardest hit by the pandemic.

Budget Year	Appropriation for Precision Medicine	Demonstration Projects Funded	Project Topics
2014–15	\$3,000,000	2	<ul style="list-style-type: none"> <li>» Pediatric cancer</li> <li>» Genetics of infectious diseases</li> </ul>
2016–17	\$10,000,000	6	<ul style="list-style-type: none"> <li>» Traumatic brain injury</li> <li>» Remote heart monitoring</li> <li>» Genomic sequencing</li> <li>» Mobile mental health</li> <li>» Multiple sclerosis</li> <li>» Prostate cancer</li> </ul>
2017–18	\$10,000,000*	3	<ul style="list-style-type: none"> <li>» Cancer health disparities</li> </ul>
2018–19	\$30,000,000**	3–5	<ul style="list-style-type: none"> <li>» Adverse Childhood Experiences</li> <li>» Additional topics (TBD)</li> </ul>

**Table 1.** Allocation of CIAPM funds.

\*Ongoing projects

\*\*\$9M of the \$30M will be used to fund three to five ACEs projects.

# Program Highlights

## COVID-19 Pandemic Response

COVID-19 brought several precision medicine and precision public health questions to the forefront: Why did some people exhibit no symptoms, while others succumbed to the disease? What was the prognosis for a patient who contracted one strain of the virus instead of another? How do we best engage individual communities to encourage and evaluate prevention, testing, and vaccination?

For many trusted partners in our precision medicine network in California, 2020 can be described as a nonstop call to action. Among countless entities rising to the challenge, including health care providers, patient advocates, government agencies, pharmaceutical companies, biomedical researchers, and the biotechnology industry, CIAPM was honored to play a part. CIAPM staff served on the Governor's COVID-19 Testing Task Force starting in April, providing research support for the assessment of diagnostic technologies. In addition, key members of the CIAPM network led efforts that significantly aided the collective response to the pandemic, facilitated in part by previous state investments in precision medicine research.

CIAPM-funded research improved the ability to track the virus

Charles Chiu, MD, PhD is a professor of infectious disease at the University of California, San Francisco (UCSF) who received CIAPM research funds from 2015-2018 to launch a multisite trial

to improve genetic sequencing tools and, for the first time, make the diagnostic test available to patients. The full project title was "Next generation sequencing for precision medicine diagnosis of acute infectious diseases." In 2020, Dr. Chiu's testing technique was one of the state's most advanced assets for tracking the spread and mutations of the SARS-CoV-2 virus.

Aided by previous state investments in their research, key members of the CIAPM network led efforts that significantly aided the response to the pandemic.

Many entities have been integral to the surveillance of COVID-19 infections in California, including the U.S. Centers for Disease Control and Prevention, the California Department of Public Health (CDPH), local public health departments, and laboratory partners. As part of the state's SARS-CoV-2 Whole Genome Sequencing Ini-

tiative, known as COVIDNet, Dr. Chiu received and sequenced specimens from counties across California to better inform public health officials about new and existing viral variants caused by mutations. Information gleaned from genetic sequencing could identify the origin of an individual's illness, indicate whether new variants were more dangerous, and help determine if interventions were effective at slowing the spread of infection.

In an April press release (*Appendix G*), Dr. Chiu stated, "I am extremely grateful for the support that the State of California has given for my work in precision medicine. It showed foresight and prepared us to respond immediately to the current crisis with real-time genomic sequencing."

### Governor's COVID-19 Testing Task Force

Three CIAPM staff members served on the Governor's COVID-19 Testing Task Force (TTF), co-led by CDPH, Blue Shield of California, and Kaiser Permanente throughout the year. The mission of the TTF was to reduce transmission of COVID-19 and support public health by improving the accessibility, equity, timeliness, and sustainability of testing. On the TTF website, the mission is summarized as elevating "the right test, for the right situation, at the right time," conveying a clear nexus with the principles of precision medicine and CIAPM.

CIAPM's Dr. McCall and Dr. McCullough contributed to the Testing Options Workstream (later renamed Testing Innovations), which focused on analyzing new diagnostic technologies. Led by Dr. Sharon Messenger of CDPH, frequent

meetings gathered experts from academia, health care, local public health departments, and state government to address topics related to novel techniques, logistical barriers, supply concerns, and future needs. Among other roles, CIAPM staff generated weekly literature reviews of relevant research studies, coordinated meetings, and provided synopses of topical national and international meetings and webinars, including from the U.S. Food and Drug Administration and Association of Molecular Pathology. CIAPM's Dr. Muir contributed to the Logistics and Operations Workstream, which focused on supply chain challenges, equitable distribution of testing sites, and provided guidance to local health jurisdictions about maximizing their impact and integrating with contact tracing efforts.

### Governor's Future Opportunities Task Force

OPR Director Gordon served as Co-Deputy Lead of the Governor's Office of Emergency Services' Future Opportunities Task Force, which approached avenues for bolstering the resiliency of state government by considering lessons learned from the pandemic and applying them to mid- and long-term practices. In support of Director Gordon's membership on the Task Force, Dr. McCullough gathered, synthesized, and wrote a summary of guidance on vaccine distribution based on historical epidemics. This included working with partners within the state at the California Department of Public Health and the California Health in All Policies Task Force as well as leading epidemiologists from UCSF, UC Berkeley, and UCLA.

## California Precision Medicine Advisory Council

The Initiative has long benefitted from the guidance of precision medicine leaders from a variety of sectors. In 2019, CIAPM initiated the creation of the California Precision Medicine Advisory Council, which was designed to ensure that the Initiative continues to benefit from broad and diverse expertise.

Building the Council began with a public call for nominations in the fall of 2019. In early 2020, OPR, in partnership with the California Health and Human Services Agency, Assembly, and Senate, finalized the Council's membership. The Council comprises:

- ▶ Seven members invited by OPR
- ▶ One member recommended by the Speaker of the Assembly
- ▶ One member recommended by the Senate President Pro Tempore
- ▶ The Secretary or an Assistant Secretary of the California Health and Human Services Agency, *ex officio*
- ▶ The Surgeon General of California, *ex officio*

The initial term lengths of the Council members were staggered to ensure continuity as members rotate off the Council. The full Council Guidelines can be found in *Appendix F*.

The Council first met on May 12. Subsequent quarterly meetings were held in August and November.

Early on, the Council was tasked with determining which outstanding precision medicine issues, if addressed, would provide significant and timely benefits to the widest range of Californians.

## California Precision Medicine Advisory Council Members



**Nadine Burke Harris, MD, MPH**  
Surgeon General of California  
**Member type:** *ex officio*



**Ysabel Duron**  
Latino Cancer Institute  
**Member type:** OPR



**Oliver Keown, MD**  
Intuitive Ventures  
**Member type:** OPR



**Kenneth Kim, MD**  
Ark Clinical Research  
**Member type:** Assembly



**Chair Clara Lajonchere, PhD**  
UCLA  
**Member type:** OPR



**Bonnie Maldonado, MD**  
Stanford University  
**Member type:** OPR



**Fatima Muñoz, MD**  
San Ysidro Health  
**Member type:** Senate



**Samar Muzzafar, MD**  
Assistant Secretary of the CA Health and Human Services Agency  
**Member type:** *ex officio*

This led to the creation of two working groups. The Data Integration Working Group will examine the collection and integration of Social Determinants of Health (SDOH) data into Electronic Health Records (EHRs), and how to best link this information to other health data. The Equitable Consent Working Group will facilitate the development of culturally and linguistically appropriate consent protocols for research, to ensure informed and empowered partnerships between patients, their care teams, and researchers.

The working groups will meet bi-monthly, independent of full Council meetings, to advance projects within their respective subject areas. CIAPM staff will work with each group to create workplans that are effective and well-suited to available resources.

### Data Integration Working Group

**Chair:** Hakan Sakul, PhD

**Members:** Oliver Keown, Clara Lajonchere, Bonnie Maldonado, Sumar Muzaffar, Fatima Muñoz, Mary Anne Schultz, Keith Yamamoto

“A traditional medical record doesn’t give a health care provider a complete picture of the many factors that contribute to a patient’s health and wellness. Risk factors such as food or housing insecurity have an enormous impact on health, but there is presently no consensus about the best way to access data about social drivers of health so that the information can be used in clinical decision making. We’re looking forward to breaking down data integration barriers for the benefit of Californians.”

–Dr. Hakan Sakul

## California Precision Medicine Advisory Council Members (cont.)



**Hakan Sakul, PhD**

Pfizer

**Member type:** OPR



**Mary Anne Schultz, PhD, MBA, MSN, RN**

CSU San Bernardino

**Member type:** OPR



*Vice Chair* **Keith Yamamoto, PhD**

UCSF

**Member type:** OPR

### Equitable Consent Working Group

**Chair:** Kenneth Kim, MD

**Members:** Ysabel Duron, Clara Lajonchere, Fatima Muñoz, Hakan Sakul, Keith Yamamoto

“The communities experiencing disparities have historically been preyed upon by medical researchers, so they are understandably reticent to participate in research that may benefit them. It’s the responsibility of medical researchers to learn why minority groups underrepresented in medical research may hesitate to participate, and work on strategies to build trust. A step forward is to design an equitable framework for the informed consent process so that it is accessible to a wider array of potential participants.”

–Dr. Kenneth Kim



## California Precision Medicine Advisory Council Chair: Clara Lajonchere, PhD



**Primary Organization:** UCLA

**Position:** Deputy Director, UCLA Institute for Precision Health

Dr. Clara Lajonchere has spent her career working on cross-cutting issues in psychiatric genetics and translational medicine. Through the Institute for Precision Health, Dr. Lajonchere works collaboratively with thought leaders across the state of California to advance precision medicine and improve outcomes for patients. Prior to UCLA, Dr. Lajonchere held faculty appointments at USC and Keck School of Medicine where she served as Director of the NIH Center for Genomic and Phenomic Studies in Autism and conducted research on models for dissemination of scientific information to underserved populations, including the Latino community. She also served as VP of Clinical Programs for Autism Speaks for over a decade, where she oversaw a diverse portfolio of basic science and clinical programs.

“Precision health is the medicine of the future. I am excited to be a part of the state’s efforts to lead the way in driving medical and scientific discoveries that will enable us to reduce health care disparities and improve the health of all Californians through a more personalized approach to treatment.”

–Dr. Clara Lajonchere



## California Precision Medicine Advisory Council Vice Chair: Keith Yamamoto, PhD



**Primary Organization:** UCSF

**Position:** Vice Chancellor for Science Policy and Strategy; Director, UCSF Precision Medicine

As UCSF's first Vice Chancellor for Science Policy and Strategy, Keith Yamamoto leads efforts to anticipate the needs of an increasingly dynamic biomedical research endeavor, and to position UCSF optimally. Throughout his career, Dr. Yamamoto has focused on the practice and communication of science, education and mentoring, peer review, and advocacy for federal support for research. He also directs a basic research lab, making groundbreaking discoveries focused on signaling and transcriptional regulation by nuclear receptors. As Chair of the National Academy's Board on Life Sciences, he created the study committee that produced *Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease*.

“Achieving the goals of precision medicine will depend on our ability to integrate and analyze massive data sets and myriad data types across basic-, clinical-, and population-level research, across engineering, computational sciences, and life sciences, and across sectors, with partnerships between academia, industry and government. Such integration will produce transformative scientific advances, and precise diagnostics, therapeutics, and prevention measures.”

–Dr. Keith Yamamoto

## Adverse Childhood Experiences Research Grants Selection

This effort brought together applications from leading experts on Adverse Childhood Experiences (ACEs) in California with a selection committee composed of the most esteemed researchers in North America.

ACEs refer to 10 types of adversity faced by children ages 0-17, categorized into three domains: 1) child abuse (physical, emotional, or sexual); 2) neglect (physical or emotional); and 3) household challenges (growing up with mental illness, substance dependence, parental separation or divorce, incarceration, or intimate partner violence within the household). Toxic stress, triggered by ACEs, is the excessive and persistent activation of the physiological stress response system during development, and can lead to long-term biological changes that contribute to poor health and social challenges throughout the lifespan.

CIAPM issued a Request for Proposals (RFP) on December 3, 2019 to award \$9 million total for research demonstration projects that address the health impacts of ACEs through collaborative precision medicine approaches. Due to the pandemic, the application process was delayed to accommodate applicants' deployment to the front lines of health care systems and research labs. As a result, the selection process was elongated, and awardees will be announced in March 2021.

The RFP topic addresses a core priority of California Surgeon General Dr. Nadine Burke Harris by supporting research that uses a precision medicine approach to improve prevention, diagnosis, measurement, and treatment of ACEs. CIAPM will award three to five proof-of-principle

## Adverse Childhood Experiences RFP: Expert Selection Committee



**Chair Melissa T. Merrick, PhD**  
Prevent Child Abuse America



**Saida Abdi, PhD, MSW, LICSW**  
University of Minnesota



**Larissa Avilés-Santa, MD, MPH**  
National Institute on Minority Health and Health Disparities



**Zulfiqar A. Bhutta, PhD, MBBS**  
The Hospital for Sick Children



**Keith Dobson, PhD**  
University of Calgary



**Willarda Edwards, MD, MBA**  
American Medical Association  
(Trustee)



**Dylan G. Gee, PhD**  
Yale University



**Jacob Ham, PhD**  
Icahn School of Medicine at Mount Sinai

demonstration projects, with the aim to address ACEs through collaborations between academic, community, public, nonprofit, and private partners. Additional funds may become available to awarded projects to examine and potentially select and use a common data-sharing platform.

Children who experience high levels of stress and/or trauma demonstrate lifelong vulnerabilities to numerous physical and mental disorders linked to the effects of a disrupted physiological stress response on the neuro-endocrine-immune system and/or gene regulation.

At present, few studies have been conducted to unravel the complex roles ACEs play in human physiology and health throughout life. Outcomes of successful proposals may include, for example, new biomarkers predictive of individual risk for future negative health outcomes, understanding individual variation in response to therapeutic approaches, and impacts of ACEs on diverse communities reflective of California's population.

Beginning in summer 2021, three-year projects will take place in California and be co-led by at least one academic research institution and at least one nonprofit community or county institution that provides support for individuals with ACEs. Research teams are encouraged to engage additional nonprofit or for-profit organizations in the community as well as industry partners. Three stages comprise the selections process: (1) submission of letters of intent to submit concept proposals; (2) submission of concept proposals; and (3) submission of full proposals, based on selected concept proposals. After the selection committee presents its recommendations for awards, CIAPM will work with awardees to develop concrete

## Adverse Childhood Experiences RFP: Expert Selection Committee



**H. Eugene Hoyme, MD**  
Sanford Children's Genomic  
Medicine Consortium



**Patricia Kerig, PhD**  
University of Utah



**Liliana J. Lengua, PhD**  
University of Washington



**Lloyd Michener, MD**  
Duke School of Medicine



**Charles A. Nelson III, PhD**  
Harvard Medical School



**Kenneth S. Ramos, MD, PhD**  
Texas A&M Institute of  
Biosciences and Technology



**Arash Shaban-Nejad, PhD, MPH**  
University of Tennessee Health  
Science Center & Oak Ridge  
National Laboratory

metrics and goals to track the progress of the demonstration projects, examine and potentially select a common data-sharing platform, and enter into contracts with OPR.

Following the December 2019 call for applicants, CIAPM received 39 letters of intent from 17 academic research institutions and 30 concept proposals from 14 institutions. The Selection Committee met virtually on August 28 and narrowed the applicant pool to 12 finalists, representing seven institutions. The Selection Committee will meet again in March 2021 to determine which finalists will be recommended for awards.

### Expert Selection Committee

CIAPM recruited and invited 15 out-of-state experts to serve on the ACEs RFP Selection Committee. Members represent the fields of precision medicine, Adverse Childhood Experiences, community engagement, big data, and trauma, among others.

### **Roadmap for Resilience**

CIAPM is honored to have supported the Office of the California Surgeon General throughout the development of *Roadmap for Resilience: The California Surgeon General's Report on Adverse Childhood Experiences, Toxic Stress, and Health*, released December 9, 2020. The 438-page, cross-sector resource is dedicated to addressing Adverse Childhood Experiences (ACEs) and the associated impacts of toxic stress that lead to long-term negative social and health challenges. This special effort relied on a rigorous scientific framework and drew upon the expertise of leaders across disciplines and geographic regions to

DECEMBER 09, 2020

# Roadmap for Resilience

The California Surgeon General's Report on Adverse Childhood Experiences, Toxic Stress, and Health



## CIAPM's roles in California's first-ever Surgeon General's Report

### Co-author

Co-Director Dr. Julianne McCall

### Contributing Author

Science & Technology Policy Fellow Dr. Ken McCullough

### Contributors

Co-Director Dr. Shannon Muir  
Policy Fellow Hyunsoo Gloria Kim

### Designer

Science Communication Specialist & Administrator Megan Varvais

### Reference Managers

Policy Fellows April Booth and Aiyana Cortez



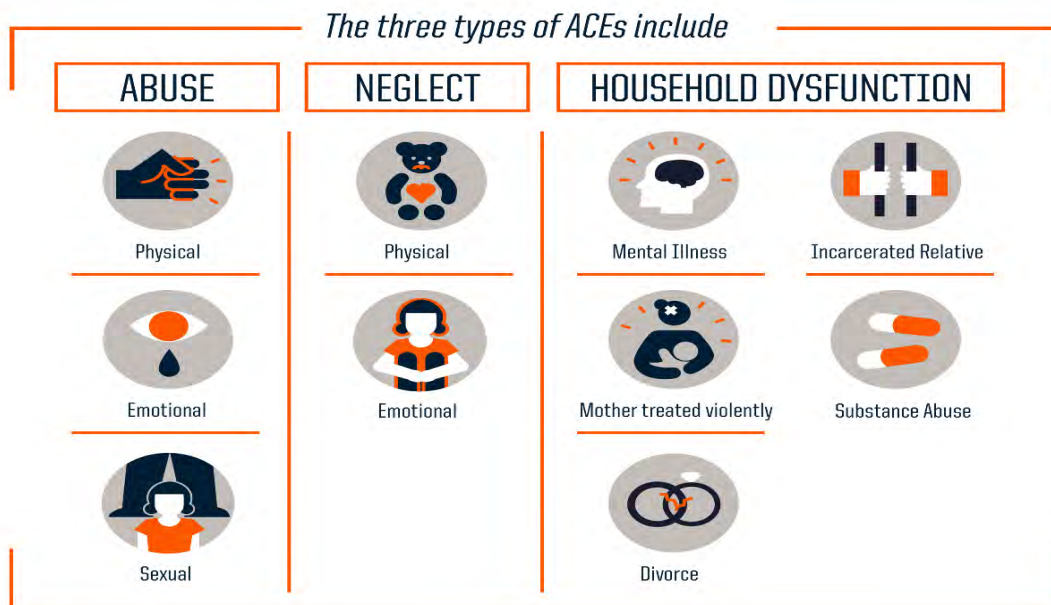
provide evidence-based approaches to prevention strategies for ACEs and toxic stress.

### Tackling ACEs in California

Of significant concern is a strong association between ACEs and very common and serious health conditions. Nine out of the 10 leading causes of death in the United States, including heart disease, cancer, and Alzheimer’s Disease or dementia, are strongly associated with ACEs. ACEs are further associated with critical social problems, such as unemployment, poverty, and felony charges. ACEs and toxic stress result from – and contribute to – detrimental and costly societal and health outcomes, creating a positive feedback loop with intergenerational accumulation of impacts within Californian communities and beyond.

Data collected over the 2011-2017 period have shown that ACEs are widely prevalent in California, with 62.3% of adults in California having experienced one or more ACEs, matching what is seen for the national population. Later analyses revealed that approximately one in six Californians have experienced four or more ACEs, and that already-disadvantaged individuals and communities (e.g., those racially marginalized, unemployed or unable to work, in lower income brackets, involved in the justice system, etc.) face higher prevalence of ACEs.

In 2019, the State of California laid out the goal of reducing ACEs by 50% within one generation in order to transform negative outcomes through intentional effort from every sector to realign social, economic, research, and health goals and structures towards addressing this public health



*ACEs are 10 kinds of adversity faced by children 0–17, categorized into three domains. Infographic courtesy of the Robert Wood Johnson Foundation.*

crisis at hand. As we simultaneously work to mitigate and overcome additional public health emergencies, such as the COVID-19 pandemic and systemic racism, *Roadmap for Resilience* highlights the importance of developing and implementing trauma-informed systems and infrastructure, rooted in the core values of prevention and equity. Included in the report are stand-alone summaries for various sectors, including health care, education, early childhood, justice, and social services. The *Roadmap for Resilience* lays out a way forward with ACEs mitigation and prevention, offering solutions, models, and best practices that address the wide diversity of needs that come from the richly diverse population of California.

## Capitol Collaborative on Race and Equity

The Capitol Collaborative on Race and Equity (CCORE) is a group of California state government agencies working together to implement racial equity awareness, training, and practices into their organizational culture. OPR is a member of the 2020-2021 CCORE Learning Cohort, with representatives from each of OPR's programmatic teams attending monthly trainings to increase their capacity for operationalizing racial equity practices in every aspect of their work. The trainings included:

- ▶ A study of the foundational history and concepts of race in America.
- ▶ Exercises to frame and reframe the language used about race, personal history, and privilege.

- ▶ An introduction to the Results-Based Accountability™ tool, developed by Mark Friedman.
- ▶ Analysis of the root causes of racism and inequities within participants' purview.

CIAPM has already used the root cause analysis to guide project planning for the Equitable Consent Working Group. In 2021, members of the learning cohort will begin creating Racial Equity Action Plans (REAP) for their respective agencies. In 2020, the California Strategic Growth Council (SGC), a cabinet-level body chaired by OPR Director Kate Gordon, adopted a cross-agency racial equity resolution, a landmark vote resulting from staff engagement in the same CCORE Learning Cohort process.

## Inter-Agency Cooperation

In addition to the Governor's COVID-19 Testing Task Force, CIAPM staff served a number of inter-agency efforts toward reducing health disparities and addressing top priorities of the Administration, including:

- ▶ CA Surgeon General's Trauma-Informed Primary Care Advisory Committee (member)
- ▶ CA Surgeon General's Senior Leadership Team (member)
- ▶ CA Essentials for Childhood Initiative Consortium (member)
- ▶ CA Health in All Policies Task Force (support)

# Demonstration Projects

## Current Demonstration Projects

Although precision medicine approaches hold promise, they are still fairly limited in application. Creating models of access for all communities is vital if the emerging scientific field is to address health disparities and have a positive impact on outcomes across socio-economic and ethnic groups.

CIAPM's current demonstration projects, initiated in late 2019, support collaboration across academic, community, nonprofit, and private partners to improve access to precision medicine cancer care for patients suffering from cancer health disparities. Each of the projects is co-hosted by a team comprised of leaders from an academic institution, cancer patient advocacy group, and a community clinic focused on underserved populations, using the principles of authentic community engagement.

All demonstration projects must:

- ▶ Integrate two or more types of “omics” data, e.g., genomics, exposomics (data regarding exposure to substances such as pollution), proteomics, pharmacogenomics; and
- ▶ Develop precision medicine capabilities that can be utilized beyond the scope of the funded projects, such as new consortia, collaborations, personnel competencies, databases, datasets, software development, patient cohorts, and participant communities and networks.

The projects present an opportunity to engage and build trust with communities historically under-represented in biomedical research in order to learn from them the barriers they face when accessing health care and participating in research studies, and to create strategies to overcome those barriers.

Creating access for all communities is vital if emerging scientific fields are to address health disparities and have a positive impact on outcomes across socioeconomic and ethnic groups.

Importantly, these projects address disparities at every stage of cancer care: prevention, screening, diagnosis, treatment, outcomes, and end-of-life care.



## Authentic Community Engagement

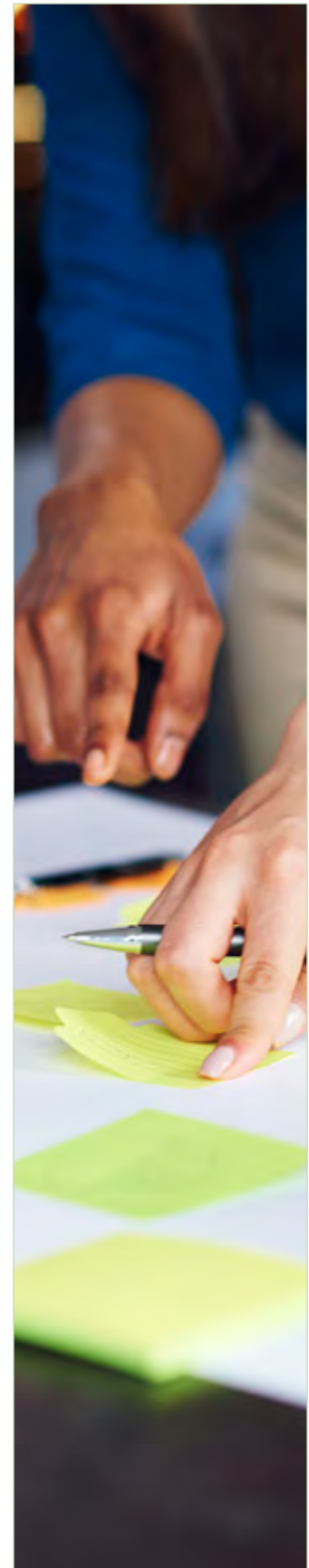
Community engagement is the process of working collaboratively with groups of people with respect to issues affecting their wellbeing.<sup>3</sup> Principles of community engagement include:<sup>4</sup>

1. Be clear about the purposes or goals of the engagement effort.
2. Become knowledgeable about the community's culture, economic conditions, social networks, political and power structures, norms and values, demographic trends, history, and experience.
3. Go to the community, establish relationships, build trust, work with the formal and informal leadership, and seek commitment from community organizations and leaders.
4. Remember and accept that collective self-determination is the responsibility and right of all people in a community.
5. Partnering with the community is necessary to create change and improve health.
6. All aspects of community engagement must recognize and respect the diversity of the community.
7. Community engagement can only be sustained by identifying and mobilizing community assets and strengths and by developing the community's capacity and resources to make decisions and take action.
8. Organizations that wish to engage a community as well as individuals seeking to effect change must be prepared to release control of actions or interventions to the community.
9. Community collaboration requires long-term commitment by the engaging organization and its partners.

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3 Centers for Disease Control and Prevention. *Principles of community engagement (1st ed.)*. Atlanta (GA): CDC/ATSDR Committee on Community Engagement; 1997.

4 Center for Disease Control and Prevention (CDC). (June 2011). *Principles of community engagement. Second edition*. [http://www.atsdr.cdc.gov/communityengagement/pdf/PCE\\_Report\\_508\\_FINAL.pdf](http://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf)



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## Reducing Cancer Disparities Through Innovative Community-Academic Partnership to Advance Access and Delivery of Precision Medicine in Monterey County (2019-2023)

Lead Principal Investigator *Dr. Manali Patel, Stanford University*

Partners *Cancer Patients Alliance, Clinica de Salud del Valle de Salinas, Community Hospital of Monterrey Peninsula, Latino Cancer Institute, Natividad Medical Center, Pacific Cancer Care*

Low-income and minority populations experience disproportionately high rates of cancer incidence and mortality, lower rates of evidence-based cancer care, and increased rates of untreated symptoms compared with non-minority patients. The objective of this project is to develop, implement, and evaluate a Community Health Worker (CHW) approach that increases access to precision medicine at every stage of cancer care.

During 2020, Dr. Patel and her team worked closely with the project's Community Advisory Board (CAB) they had established in 2019. The CAB is comprised of dozens of stakeholders from a variety of sectors including industry, government, public and private healthcare and clinic systems, along with advocates and survivors. The research team hosted three CAB meetings during 2020 (all held virtually due to the pandemic), and sent out three newsletters to provide regular project updates to the CAB members. The research team is quantitatively measuring the ongoing success and engagement of the CAB by sending out periodic evaluations.



### Community Health Workers

Community Health Workers (CHWs) are lay members of the community who work either for pay or as volunteers in association with the local healthcare system, in urban and rural environments. CHWs usually share ethnicity, language, socioeconomic status, and life experiences with the community members they serve. They are known by many titles: community health advisors, lay health advocates, *promotoras* or *promotores*, outreach educators, community health representatives, peer health promoters, and peer health educators. CHWs offer interpretation and translation services, provide culturally appropriate health education and information, give informal counseling and guidance on health behaviors, advocate for individual and community health needs, and provide some direct services such as first aid and blood pressure screening.<sup>5</sup>

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<sup>5</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Health Professions. (2007). *Community Health Worker National Workforce Study*.

To optimize cancer care for low-income and minority populations, specific approaches, or interventions, must be designed that take into account linguistic, cultural, and financial realities of the communities that the interventions will serve. Customizing interventions for communities is a hallmark of precision medicine, and partnering with the community is essential to the development of effective interventions. To design an intervention, the researchers gathered input and identified barriers to cancer care by conducting a series of in-person focus groups. They first developed sets of guidelines for conducting focus groups with two types of populations. One set of guidelines was for focus groups for community members who are undergoing cancer prevention and screening, and the second was for patients who have been diagnosed with cancer, their caregivers, and their care providers including physicians, social workers, and behavioral health practitioners. The team also developed a guide for conducting standardized interviews with other stakeholders including health system executive staff, clinical staff, and community health workers, in order to obtain feedback on project implementation.

The research team was initially able to complete a focus group for 12 cancer care providers and stakeholders. Major themes that arose from this focus group included that:

- ▶ Latino patient populations and other non-English speaking populations lack the resources necessary to navigate the health system.
- ▶ Low-income and minority patients experienced significant language and financial barriers after

cancer diagnosis.

- ▶ High-quality care for patients undergoing treatment requires extensive coordination.
- ▶ Discussions with patients about intricacies of care, especially when discussing cancer care, treatment, and genetic and molecular tumor testing, benefit from facilitation by CHWs.

The project team also completed interviews with 11 key cancer care delivery stakeholders to obtain feedback on overall planned project implementation. These stakeholder interviews provided the team with insight about the local context, assets, and barriers to achieving cancer health equity in Monterey County. The interviewed stakeholders emphasized the need to focus on:

- ▶ Ensuring insurance coverage and financial support for screening and diagnosis services, specifically genetic testing.
- ▶ Outreach programs including health fairs and word-of-mouth approaches.
- ▶ Using CHWs to assist in advocating for insurance and financial concerns and outreach activities.

The advent of COVID-19, including the stay at home order, prevented the team from holding additional in-person focus groups and interviews with patients and their caregivers. The researchers eventually shifted to conducting interviews with cancer patients and care providers by telephone. The team also added COVID-related questions to the interviews, recognizing that valuable data about the intersection of COVID and cancer care in minority communities could be captured using the existing study infrastructure. Dr. Patel and her team additionally drafted two surveys to

understand unmet COVID needs. One survey was specifically for cancer patients, and the other was geared toward the broader community.

In 2021, Dr. Patel and her team of investigators plan to work with the CAB and continue taking steps to design the CHW precision medicine cancer care intervention, and lay the groundwork to implement and evaluate the intervention they develop.

Since the projects' inception, the team has received in-kind support from Stanford University Medical School's Valley Fellows program, which is sponsored by The Valley Foundation and provides Stanford medical students with the opportunity to work on and learn about community-responsive research projects. The estimated in-kind support for 2020 is \$50,000.

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### **Integrated Machine-Learning Platform to Inform Precision Therapy in Underrepresented Triple-Negative Breast Cancer Patients (2019–2022)**

**Lead Principal Investigators** *Dr. William Kim and Dr. Pablo Tamayo, UC San Diego*

**Partners** *American Cancer Society, Cancer Resource Center of the Desert, El Centro Regional Medical Center, Michigan State University, Moores Cancer Center, Quality Partners, Rady Children's Hospital, San Diego State University, Sanford Burnham Prebys Medical Discovery Institute, Tri-City Medical Center, University of Guadalajara*

Despite recent progress in the development of new cancer medications, Triple-Negative Breast Cancers (TNBCs), the most aggressive group

of breast cancers, remain largely untreatable. TNBCs are resistant to many currently approved treatments and TNBC tumors grow faster and are more likely to metastasize compared to other breast cancers, and lead to higher mortality rates. TNBCs are reported to be prevalent among Hispanic women, representing a major health disparity in cancer diagnosis and treatment. This project brings together a community of researchers, clinicians, patients, and community advocates, joining forces as 'Project CELSUS' to apply precision medicine genomic profiling to identify novel treatments and implement a more precise and rational system to match TNBC tumors and cancer therapies.

Since launching in August 2019, the Project CELSUS team has made important strides towards developing project infrastructure and bringing together stakeholders from 14 separate institutions. One of the early goals was to compile and analyze information about clinical breast tumors from several large, public datasets including The Cancer Genome Atlas, Cancer Cell Line Encyclopedia, and Gene Expression Omnibus. The UC San Diego team has developed a prototype of a database that combines the information from these datasets with additional clinical data that had previously been collected by CELSUS team members. Project CELSUS has collaborated with UC San Diego Health Information Services and Amazon Web Services to develop a secure, HIPAA-compliant, cloud-based data repository to store and track patient samples.

Another goal of Project CELSUS is to develop a computational disease model to define a taxonomy of functional cellular states and archetypes



for TNBC, to eventually help oncologists optimize treatment for patients by analyzing tumors in a way that would enhance the ability to predict how a tumor would react to medication, or a combination of medications. The team analyzed the data from their prototype database to design a model system to classify TNBC tumors into subtypes by identifying patterns within tumors' molecular signatures and comparing those signatures with clinical outcomes. The researchers identified molecular signatures that were associated with a subset of particularly aggressive TNBC tumors and have observed a potentially significant association between a patient's ethnicity (African American and Hispanic ancestry), BMI, and tumor aggressiveness. The researchers plan to incorporate additional data into the model in order to refine its classification system.

Of note, the team's model suggests that combining two specific medications, which both happen to already be approved by the FDA, could be highly effective against a type of TNBC tumor that is known to be particularly aggressive and resistant to other therapeutics.

Project CELSUS has made strides to strengthen the research capabilities of the community clinics that are central to the collaborative team. The team members from the community clinics experience challenges when participating in research, principally because the time they spend attending project meetings is time that can't be spent seeing patients. The Project CELSUS team has been working to create the systems and infrastructure so that the community investigators can efficiently receive subawards, share patient data and tissue samples, train clinic staff,



### Aulus Cornelius Celsus

Aulus Cornelius Celsus (25 BC–50 AD) was an early pioneer of evidenced-based medicine in the Roman Empire. His treatise *De Medicina* covered topics including the history of medicine, the ethics of human and animal experimentation, pathology, anatomy, pharmacology, surgery, and orthopedics.<sup>6</sup> Celsus advocated for the use of data across many fields, including medicine, agriculture, and law, writing, "Before accepting any belief one ought to follow reason as a guide, for credulity without enquiry is a sure way to deceive oneself."

6 *"On Medicine - De medicina". World Digital Library. Retrieved 2021-03-12.*

register research protocols, and send samples for sequencing to third-party vendors. In addition, through community outreach and engagement, the Project CELSUS team is conducting formal interviews in Spanish and English with community clinicians and Latina breast cancer patients across San Diego and Imperial County.

The COVID-19 pandemic caused unavoidable delays to the team's work. The investigators are working with CIAPM staff to update their project timeline and amend their contract with OPR.

The Project CELSUS team plans to build on its 2020 accomplishments by improving the project models, refining the system for testing the effectiveness of medications, validating results in additional models, and continuing to strengthen engagement with partnering community hospitals. The work will support the ultimate goal of optimizing treatments for Hispanic women with TNBC.

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## **Addressing Disparities in Breast Cancer in Latinas: A multi-tiered approach (2019-2022)**

**Lead Principal Investigator** *Dr. Elad Ziv, UC San Francisco*

**Partners** *Bay Area Cancer Connections, City of Hope, Latino Cancer Institute, Pomona Health, Stanford University, UC Davis, Vision y Compromiso, Zuckerberg SF General*

Breast cancer is the leading cause of cancer death among Latinas in California. Understanding hereditary cancer risk can help improve screening and detection by identifying women who should start screening at an earlier age, and also receive

screening more often and with more accurate methods. This project aims to better understand which genetic variants cause Latinas to develop breast cancer, and to increase community awareness of hereditary cancer and genetic testing.

Dr. Ziv and his team of investigators made progress toward several milestones in 2020 despite the COVID-19 pandemic causing delays and necessitating significant shifts from the project's original plan.

The team has identified some previously unknown genetic variants that may contribute to the development of breast cancer in Latinas by examining DNA sequences from over 4,000 Latina women who developed breast cancer, and comparing them to data from over 4,000 Latina women who did not develop breast cancer. The investigators are using a similar method to refine Latina women's polygenic risk scores, which take into account all a person's individual genetic variants to calculate a sum total of their risk of developing breast cancer.

In addition to using existing databases for their analysis, the project team is also recruiting new women for the study after receiving access to names of potential study participants from the California Cancer Registry, which collects information about almost all cancers diagnosed in California. The COVID-19 pandemic delayed the ability to recruit patients, but Dr. Ziv and his team resumed recruitment in the last half of 2020. In the interim, they built the infrastructure to track recruitment, eligibility, and collection of tissue samples.

The team is researching the DNA of Latina women and their propensity to develop cancer, and investigating the DNA and RNA profiles of breast tumors from Latinas. In these analyses they are investigating the somatic mutations (the mutations that the cells gain during the process of cancer development). They are comparing these profiles to existing mutation profiles from other populations in an attempt to understand what may be unique in this population and how that may affect how women respond to cancer treatment. The team is in the process of collecting tumor and blood samples from Latina patients at City of Hope and isolating the DNA and RNA for sequencing.

Another aim of the project is to educate members of the Latina community about hereditary breast and ovarian cancer by training promotores to teach fundamentals of cancer, genetic heritability, and screening. 24 promotores have been trained using a combination of in-person and virtual training sessions. Of the trained promotores, four are actively educating the community in northern California and eight in southern California. They have educated more than 474 community members; of these, 419 have completed family histories which will allow the investigators to identify those who may benefit from genetic counseling. 33 women were identified as having enough family history as to recommend genetic counseling to them or a member of their family. Fourteen percent of the women that attended the education session were not up to date regarding screening mammography despite being 45 years of age or older. The researchers navigated these women to their appointments. COVID-19 required



### The California Cancer Registry

The California Cancer Registry (CCR) is a program of the California Department of Public Health's Chronic Disease Surveillance and Research Branch.<sup>7</sup> It is a state-wide population-based cancer registry that collects information about almost all cancers diagnosed in California. CCR aggregates this data, performs many phases of quality control, and analyzes the data on a statewide basis. Scientists can apply to access CCR data for research purposes.

7 <https://www.ccrca.org/learn-about-ccr/>

the in-person education program shift to a virtual platform, which created several challenges including that members of the target communities were sometimes unfamiliar with the technology and required significant assistance from the promotores. Additionally, many community members either contracted COVID-19 themselves or were caring for someone who had, and their priorities understandably shifted away from potential hereditary cancer risk to more immediate health issues.



Despite these challenges, the promotores were able to adapt and are now educating women at the originally proposed rate.

Dr. Ziv and his team are also working to assess the policy and economic implications of genetic testing. Use of precision medicine approaches, including genetic testing, can be limited by health insurance coverage. Latinas in California are more than twice as likely than other populations to be insured by Medi-Cal or to be uninsured.<sup>8,9</sup> The investigators in this study wanted to gather information about current policies and usage to assess possible implications of changes to coverage of genetic tests. The investigators compared access to coverage across four different settings by gathering data from safety net and academic medical centers in both California and North Carolina.

Among their initial findings:

- ▶ Currently, access to hereditary breast and ovarian cancer testing is generally not a concern for Latinas or other populations, even in safety net clinics, because laboratories provide testing for little to no out-of-pocket cost. However, there are concerns that this business model is not sustainable, and that low-income populations will eventually lose access.
- ▶ Cascade testing, in which genetic testing is extended to blood relatives of an individual with

8 <https://www.chcf.org/publication/2019-medical-facts-figures-crucial-coverage/>

9 <https://laborcenter.berkeley.edu/racial-and-ethnic-health-coverage-inequities-in-california-would-widen-if-aca-is-overturned>

a disease-causing variant, is a particular issue of concern for Latina patients; many were unsure they would be able to contact relatives, or that their relatives would be able to access testing, especially for those relatives who live outside the United States.

- ▶ Looking only for specific known mutations that may cause cancer isn't sufficient to catch all risk-inducing variants because some variants are more common in Latinas than in the broader population.

In 2021, Dr. Ziv and his team plan to continue their work addressing breast cancer disparities in Latinas by defining unique genetic factors that may increase the risk of developing breast cancer, and engaging with the community to increase overall familiarity with hereditary cancer and genetic testing.

## Former Projects Overview

Eight of the 11 collaborative research projects funded by CIAPM since its establishment in 2015 have concluded. CIAPM worked with outside evaluators on a formal process to examine project milestones and outcomes, culminating in a report presented to the Legislature in 2019.<sup>10</sup> Recognizing that research results continuously build on preceding work and not all long-range outcomes surface during the limited timeframe of a funding cycle, CIAPM maintains close connections with all former grantees in an effort to monitor new developments in projects building on past CIAPM

10 [http://opr.ca.gov/ciapm/docs/20200327-Evaluations\\_Report\\_CIAPM\\_Projects\\_2015-2018\\_update.pdf](http://opr.ca.gov/ciapm/docs/20200327-Evaluations_Report_CIAPM_Projects_2015-2018_update.pdf)

support. To date, CIAPM-funded research has generated 67 (33 in 2020) publications, 98 (18 in 2020) presentations, 28 (10 in 2020) press events or articles, and 5 (all in 2020) patents or patent extensions. To view all publications, presentations, and articles from 2020, see *Appendix A*. Previous works are detailed in *Evaluations of California Initiative to Advance Precision Medicine Projects, 2015-2018* and CIAPM's 2019 Annual Report.

Especially during a pandemic, when biomedical researchers and clinicians were called to action to drive the state's science-based, equity-focused response, CIAPM closely followed each contribution of former grantees. The first two precision medicine demonstration research teams funded by CIAPM in 2015-2018, for example, led expansive, avant-garde efforts to combat the pandemic, covered earlier in this report (Section: **COVID-19 Pandemic Response**).

# Network Engagement

CIAPM's enabling statute primarily tasks the program with funding grants for precision medicine demonstration projects. The Legislature also imagined the Initiative as a way to maximize the intersection of data infrastructure, medicine, and biomedical research by coordinating the efforts of public, private, and nonprofit partners throughout California. This coordination includes staff contributions to scientific discourse, maintaining the California Precision Medicine Asset Inventory, and frequent communication with our network through multiple mediums.

## Rare Disease Caucus Informational Hearing

On August 12, the California Rare Disease Caucus hosted an Informational Hearing on Rare Access During COVID and Beyond, co-chaired by Assemblymembers Rob Bonta (18th District), Brian Maienschein (77th District), and Marie Waldron (75th District). The hearing granted an opportunity for CIAPM Co-Director Dr. McCall to provide an overview of precision medicine and its role in diagnosing, treating, and curing rare diseases. In this hearing, Dr. McCall described how precision medicine "places humans at the center of health care" through its understanding that social and work environments affect our physical and mental wellbeing. She spoke to how, in real time, "our modern technical capacities are beginning to factor into health decisions for a more holistic

view of each individual."

Dr. McCall also explained how CIAPM works to "expand precision medicine approaches to underrepresented communities and foster the creation of new technologies and therapies for diverse populations" through coordination of public, private, and non-profit partners and direct support of pioneering projects that aim to reduce health disparities and improve health outcomes by capitalizing on the powerful potential of precision medicine.

A link to the recording of the full hearing and the agenda can be found in *Appendix H*.

## Asset Inventory

CIAPM maintains an inventory of precision medicine assets in California. Assets include published data sets, individual researchers, academic and commercial laboratories, campus institutes, and community groups. The goal of the inventory is to facilitate outreach efforts and cross-sector partnerships by helping California-based researchers, clinicians, community groups, and industry partners easily find each other, based on criteria like disease focus, research type, or geographical location.

The California Precision Medicine Asset Inventory, initially built through pro bono support from Lawrence Berkeley National Laboratory, was launched in parallel with the ACEs RFP in December 2019. Over the next 12 months, CIAPM led

a comprehensive outreach campaign to contact every organization, researcher, or group in the inventory, to affirm their inclusion and provide an opportunity to review how their organization and work are described. Researchers and organizations can also submit a request to be added to the inventory, which currently contains over 490 entries.

Initially, the asset inventory focused on assets related to CIAPM's current and upcoming research grant areas. In 2020, the inventory was expanded to include a breadth of foundational research assets in emergent topic areas. For example, in response to the COVID-19 pandemic, CIAPM undertook a deliberate campaign to add infectious disease researchers and research institutions to the inventory.

CIAPM staff plan to further improve the user experience and interface of the inventory in 2021.

## Newsletter and Social Media

CIAPM has long used an email list to communicate important announcements to our subscribers. In July 2020, CIAPM began publishing a monthly email newsletter to maintain regular communication with our network and highlight programmatic updates, feature stories about CIAPM projects, grantees, and advisors, and provide notices about upcoming external precision medicine funding opportunities and events. There is often a connection between precision health and medicine and current events, and the newsletter serves as a platform to highlight those connections.

CIAPM also expanded its outreach on social media in 2020, with an uptick in posts on OPR's

Twitter and LinkedIn feeds.

## Website Update

CIAPM strives to highlight the ongoing accomplishments of our greater network. A News section was added to the website to give the featured newsletter stories about our network of scientists, clinicians, and researchers a place of permanence. As the only state-funded precision initiative, CIAPM believes its website can and should serve as an informational resource about the broader field of precision health. To that end, CIAPM also expanded its meetings page to include external events to alert general and professional audiences about upcoming conferences and educational webinars relevant to precision medicine.

The CIAPM website was recently updated for consistency and readability for the general public. A redesign is expected to debut Spring 2021, part of a sitewide update for OPR.

## Invited Presentation and Talks

- ▶ January 13, California Institute for Regenerative Medicine, *Navigating Regenerative Medicine Roundtable*, San Francisco
- ▶ January 22, Precision Medicine World Conference, *The California Initiative to Advance Precision Medicine*, Santa Clara
- ▶ February 15, American Association for the Advancement of Science, *Science Policy for Equitable Outcomes*, Seattle
- ▶ February 16, American Association for the Advancement of Science, *Careers in State Science, Technology, and Innovation Policy*, Seattle



CIAPM Co-Director Dr. Shannon Muir presenting to the Precision Medicine World Conference in Santa Clara, CA. January 2020.

- ▶ February 27, World Economic Forum, *Genomics in the Clinic Workshop*, San Francisco
- ▶ April 23, World Economic Forum, *Genomics in the Clinic Workshop Update*, Virtual
- ▶ April 24 and May 22, World Economic Forum, *Managing Epidemics with Consumer Wearables Workshop Series*, Virtual
- ▶ May 21, UC Riverside Science to Policy Graduate Certificate Course, *Science Policy in the Executive Branch of California State Government*, Virtual
- ▶ July 23, UC San Diego, *Science Policy and Regulatory Affairs*, Virtual
- ▶ August 19, Genentech, *Business Development and Policy*, Virtual
- ▶ September 28, UC Irvine, *Science Policy Course*, Virtual
- ▶ October 20, Association for Women in Science, Sacramento Valley Chapter, *Precision Medicine and Science Policy*, Virtual
- ▶ November 17, Sonoma Forum, *Health Equity, Precision Medicine, and COVID-19*, Virtual
- ▶ November 17, UC Berkeley, *Health Equity, Precision Medicine, and Science Policy*, Virtual
- ▶ December 7–8, CSU Sacramento, *Precision Medicine and Policymaking for Health Equity*, Virtual
- ▶ December 18, Howard University Morehouse School of Medicine Science and Health Policy Group, Virtual

# Conclusion and Next Steps

Despite a global pandemic, in 2020 CIAPM exceeded its statutory responsibilities in the service of California. CIAPM staff aided the state's pandemic response by distilling and reporting the latest research findings to high-ranking officials on the COVID-19 Testing Task Force. By establishing the Precision Medicine Advisory Council, the state has not only helped to ensure the continued success of the Initiative, it also created a body of experts that can be leveraged by state policy makers to help inform them on pressing issues facing California, including the implementation of health information exchanges, genetic-information nondiscrimination, and frameworks around equitable participation in biomedical research.

2020 also saw CIAPM initiate and strengthen collaborations between state agencies and departments, including by playing key roles in the authorship of the first ever report from the Office of the Surgeon General.

In 2021, CIAPM's main goals are to:

- ▶ Select the ACEs proposals that will be funded, and launch the projects
- ▶ Support the ongoing work of the Cancer Disparities projects
- ▶ Continue to provide the Executive and Legislative Branches on-call access to expertise in the fields of precision medicine and precision public health
- ▶ Engage the Advisory Council's two working groups (Data Integration and Equitable Consent) in pursuit of their project goals
- ▶ Launch a new website
- ▶ Continue to serve the state in its recovery from the COVID-19 pandemic
- ▶ Expand upon our communications efforts



# Appendices

## A. 2020 Publications, Presentations, Press, and Patents from CIAPM Projects

### Current projects

#### **Publications**

Lee, Sanghoon, John Jun, William J. Kim, Pablo Tamayo, Stephen B. Howell. 2020 "WNT Signaling Driven by R-spondin 1 and LGR6 in High-grade Serous Ovarian Cancer". *Anticancer Research* 40, no. 11:6017-6028. <https://doi.org/10.21873/anticancer.14623>.

#### **Integrated Machine-Learning Platform to Inform Precision Therapy in Underrepresented Triple-Negative Breast Cancer Patients (Project CELSUS)**

Li, Jingting, Manisha Tiwari, Xiaojun Xu, Yifang Chen, Pablo Tamayo, George L. Sen. 2020. "TEAD1 and TEAD3 Play Redundant Roles in the Regulation of Human Epidermal Proliferation." *Journal of Investigative Dermatology* 140, no. 10:2081-2084.e4. <https://doi.org/10.1016/j.jid.2020.01.029>. **Project CELSUS**

Liu, Chao, Sayed H. Sadat, Koji Ebisumoto, Akihiro Sakai, Bharat A. Panuganti, Shuling Ren, Yusuke Goto, Sunny Haft, Takahito Fukusumi, Mizuo Ando, Yuki Saito, Theresa Guo, Pablo Tamayo, Huwate Yeerna, William Kim, Jacqueline Hubbard, Andrew B. Sharabi, J. Silvio Gutkind, Joseph A. Califano. 2020.

"Cannabinoids Promote Progression of HPV-Positive Head and Neck Squamous Cell Carcinoma via p38 MAPK Activation." *Clinical Cancer Research* 26, no. 11:2693-2703. <https://doi.org/10.1158/1078-0432.CCR-18-3301>.

#### **Project CELSUS**

Panda, Anshuman, Anupama Yadav, Huwate Yeerna, Amartya Singh, Michael Biehl, Markus Lux, Alexander Schulz, et al. 2020. "Tissue- and development-stage-specific mRNA and heterogeneous CNV signatures of human ribosomal proteins in normal and cancer samples." *Nucleic Acids Research* 48, no. 13:7079-7098. <https://doi.org/10.1093/nar/gkaa485>. **Project CELSUS**

Pham, Timothy V., Amélie Boichard Aaron Goodman, Paul Riviere, Huwate Yeerna, Pablo Tamayo, Razelle Kurzrock. 2020. "Role of ultraviolet mutational signature versus tumor mutation burden in predicting response to immunotherapy." *Molecular Oncology* 14, no. 8:1680-1694. <https://doi.org/10.1002/1878-0261.12748>. **Project CELSUS**

Ren, Shuling, Daria A. Gaykalova, Theresa Guo, Alexander V. Favorov, Elana J. Fertig, Pablo Tamayo, Juan Luis Callejas-Valera, et al. 2020. "HPV E2, E4, E5 drive alternative carcinogenic



pathways in HPV positive cancers." *Oncogene* 39, no. 40:6327-6339. <https://doi.org/10.1038/s41388-020-01431-8>. **Project CELSUS**

Rusert, Jessica M., Edwin F. Juarez, Sebastian Brabetz, James Jensen, Alexandra Garancher, Lianne Q. Chau, Silvia K. Tacheva-Grigorova, et al. 2020. "Functional Precision Medicine Identifies New Therapeutic Candidates for Medulloblastoma." *Cancer Research* 80, no. 23:5393-5407. <https://doi.org/10.1158/0008-5472.CAN-20-1655>. **Project CELSUS**

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Zavala, Valentina A., Paige M. Bracci, John M. Carethers, Luis Carvajal-Carmona, Nicole B. Coggins, Marcia R. Cruz-Correa, Melissa

Davis, Adam J. de Smith, Julie Dutil, Jane C. Figueiredo, Rena Fox, Kristi D. Graves, Scarlett Lin Gomez, Andrea Llera, Susan L. Neuhausen, Lisa Newman, Tung Nguyen, Julie R. Palmer, Nynikka R. Palmer, Eliseo J. Pérez-Stable, Sorbarikor Piawah, Erik J. Rodriguez, María Carolina Sanabria-Salas, Stephanie L. Schmit, Silvia J. Serrano-Gomez, Mariana C. Stern, Jeffrey Weitzel, Jun J. Yang, Jovanny Zabaleta, Elad Ziv, Laura Fejerman. 2021. "Cancer health disparities in racial/ethnic minorities in the United States." *British Journal of Cancer* 124, no. 1:315-332. <https://doi.org/10.1038/s41416-020-01038-6>. **Addressing Disparities in Breast Cancer in Latinas: A multi-tiered approach**

#### ***Presentations and Posters***

Brooks, Victor, Valeria Duarte, Yesica Garcia. 2020. "Cáncer de Pecho: detección y prevención." Presentaion, *Clínica de Salud del Valle de Salinas Community Meeting*, Salinas, CA, October 21. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Duarte, Valeria, Yesica Garcia. 2020. "Breast Cancer Screening and Prevention." Presented to patients at Clínica de Salud del Valle de Salinas, Salinas, CA, August 20, 31, October 13-14, and October 31. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Duarte, Valeria, Yesica Garcia. 2020 "Breast Cancer Screening and Prevention." Presented to patients at Clínica de Salud del Valle de Salinas, Salinas, CA, October 31. **Reducing Cancer Disparities Through Innovative**

### **Community-Academic Partnership**

Duarte, Valeria, Yesica Garcia. 2020 "Cancer Prevention in the Time of COVID-19." Presented to patients at Clínica de Salud del Valle de Salinas, Salinas, CA, September 9. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Duarte, Valeria, Yesica Garcia. "Cervical Cancer Detection and Prevention." Presented to patients at Clínica de Salud del Valle de Salinas, Salinas, CA, August 31. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Duarte, Valeria, Yesica Garcia. "Colorectal Cancer Detection and Prevention." Presented at Clínica de Salud del Valle de Salinas, Salinas, CA, August 20 & 31. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Duarte, Valeria, Yesica Garcia. 2020. "Lung Cancer Detection and Prevention." Presented at Clínica de Salud del Valle de Salinas, Salinas, CA, August 31. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Duarte, Valeria, Yesica Garcia. 2020. "Migrant Farmworker Health Issues and Barriers to Care." *Stanford Internal Medicine Resident Educational Conference for Stanford University*, Stanford, CA, December 9. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Duarte, Valeria, Yesica Garcia. 2020. "Prevención de Cáncer en Tiempo del COVID-19." Presentation, Breast Cancer Presentation

hosted by Migrant Education, Virtual, October 20. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Duarte, Valeria, Yesica Garcia. 2020. "Prostate Cancer Detection and Prevention." Presentation, Clínica de Salud del Valle de Salinas, Salinas, CA, August 20 & 31. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Duron, Ysabel. 2020. "The Value Added of Community Health Workers." Talk, *Stanford Internal Medicine Resident Educational Conference for Stanford University*, Stanford, CA, December 9. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Koontz, Zach. 2020. "Introducing the 'Precision Medicine in Monterey County' Project in Collaboration with Stanford." Presentation, *Pacific Cancer Care Committee Meeting*, Monterey, CA, December. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Koontz, Zach. 2020. "Introducing the 'Precision Medicine in Monterey County' Project in Collaboration with Stanford." Presentation, *Pacific Cancer Care Journal Club*, Monterey, CA, March 1. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Koontz, Zach. 2020. "Precision Medicine in Monterey County Project: expanding access for underserved communities." Informal oral presentations, Community Hospital of the Monterey Peninsula, Monterey, CA, February

12 and February 26. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Nierenberg, Jovia L., Aaron Adamson, Valentina Zavala, Paul Lott, Esther John, Donglei Hu, Scott Huntsman, Jeff Weitzel, Gabriela Torres-Mejia, Christopher Haiman, Larry Kushi, Laura Fejerman, Luis Carvajal-Carmona, Susan Neuhausen, Elad Ziv. 2020. "Common RAD52 variants are associated with decreased breast cancer risk among US Latinas and Latin American women." Abstract presentation, *UCSF Breast Oncology Program Retreat*, San Francisco, CA, February 20. **Addressing Disparities in Breast Cancer in Latinas**

O'Brien, Dale G., Oguchi Nkwocha, Romy Agustin-Garcia. 2020. "Genetic Testing and Applications of the GIA Chatbot with Invitae." Presentation, *Clínica de Salud del Valle de Salinas Provider Meeting*, Salinas, CA, February 6. **Reducing Cancer Disparities Through Innovative Community-Academic Partnership**

Takahashi, Hideyuki, Ryan M. Shepard, Marc A. Paradise, Sang Min Lee, Ann Shih, Cristina Flores-Arenas, William Kim, Judith A. Varner. 2020. "Macrophage PI3Kγ controls T cell activation and T cell memory generation through the production of IL-12." Poster, *Proceedings of the Annual Association of Cancer Research*, Philadelphia, PA, April 27-28 and June 22-24. **Project CELSUS**

Tamayo, Pablo. 2020. "Cellular and Tumor Archetypes: A Functional Taxonomy of Cancers." Presentation, *UCSD Moores Cancer Center Cancer Biology and Signaling Program*

*Retreat*, UC San Diego, CA, September 9. **Project CELSUS**

Tamayo, Pablo. 2020. "Cellular and Tumor Archetypes: A Functional Taxonomy of Cancers." Presentation, Monash University, Melbourne, Australia, November 16. **Project CELSUS**

**Press**

Fikes, Bradley. 2019. "UCSD gets \$3 million to fight triple-negative breast cancer." *The San Diego Union-Tribune*, February 15. <https://www.sandiegouniontribune.com/business/biotech/sd-me-ucsd-triple-negative-breast-cancer-20190215-story.html>. **Project CELSUS**

**Completed Projects**

All publications, presentations, press coverage, and patent submissions or updates that occurred between 2015 and 2018 are listed in the 2019 Evaluation Report, available on the CIAPM website. The following section summarizes only those from 2020.

**Publications**

Pfeil, Jacob, Lauren M. Sanders, Ioannis Anastopoulos, A. Geoffrey Lyle, Alana S. Weinstein, Yuanqing Xue, Andrew Blair, et al. 2020. "Hydra: A mixture modeling framework for subtyping pediatric cancer cohorts using multimodal gene expression signatures." *PLOS Computational Biology* 16, no. 4:e1007753. <https://doi.org/10.1371/journal.pcbi.1007753>.

**California Kids Cancer Comparison (CKCC)**

Rao, Arjun A., Ada A. Madejska, Jacob Pfeil, Benedict Paten, Sofie R. Salama, David Haussler. 2020. "ProTECT—Prediction of T-Cell Epitopes for Cancer Therapy." *Frontiers*

- in Immunology*, 11:483296. <https://doi.org/10.3389/fimmu.2020.483296>. **CKCC**
- Sanders, Lauren M., Allison Cheney, Lucas Seninge, Anouk van den Bout, Marissa Chen, Holly C. Beal, Ellen Towle Kephart, et al. 2020. "Identification of a differentiation stall in epithelial mesenchymal transition in histone H3-mutant diffuse midline glioma." *GigaScience* 9, no. 12. <https://doi.org/10.1093/gigascience/giaa136>. **CKCC**
- Bharucha, Tehmina, Clarissa Oeser, Francois Balloux, Julianne R. Brown, Ellen C. Carbo, Andre Charlett, Charles Y. Chiu, et al. 2020. "STROBE-metagenomics: a STROBE extension statement to guide the reporting of metagenomics studies." *Infectious Diseases* 20, no. 10:e251-260. [https://doi.org/10.1016/S1473-3099\(20\)30199-7](https://doi.org/10.1016/S1473-3099(20)30199-7). **Precision Diagnosis of Acute Infectious Diseases (PDAID)**
- Bove, Riley, Christa A. Bruce, Chelsea K. Lunders, Jennifer R. Pearce, Jaqueline Liu, Erica Schleimer, Stephen L. Hauser, et al. 2020. "Electronic health record technology designed for the clinical encounter: MS neuroSHARE." *Neurology Clinical Practice*. <https://doi.org/10.1212/CPJ.0000000000000986>. **Precision Medicine for Multiple Sclerosis: Making It Work**
- Broughton, James P., Wayne Deng, Guixia Yu, Clare L. Fasching, Venice Servellita, Jasmeet Singh, Xin Miao, et al. 2020. "CRISPR-Cas12-based detection of SARS-CoV-2." *Nature Biotechnology* 38, 870-874. <https://doi.org/10.1038/s41587-020-0513-4>. **PDAID**
- Chamie, Gabriel, Carina Marquez, Emily Crawford, James Peng, Maya Petersen, Daniel Schwab, Joshua Schwab, et al. 2020. "Community Transmission of Severe Acute Respiratory Syndrome Coronavirus 2 Disproportionately Affects the Latinx Population During Shelter-in-Place in San Francisco." *Clinical Infectious Diseases*, ciaa1234, <https://doi.org/10.1093/cid/ciaa1234>. **PDAID**
- Crawford, Emily D., Irene Acosta, Vida Ahyong, Erika C. Anderson, Shaun Arevalo, Daniel Asarnow, Shannon Axelrod, et al. 2020. "Rapid deployment of SARS-CoV-2 testing: The CLIAHUB." *PLOS Pathogens* 16, no. 10:e1008966. <https://doi.org/10.1371/journal.ppat.1008966>. **PDAID**
- Deng, Xianding, Wei Gu, Scot Federman, Louis du Plessis, Oliver G. Pybus, Nuno R. Faria, Candace Wang, et al. 2020. "Genomic surveillance reveals multiple introductions of SARS-CoV-2 into Northern California." *Science* 369, no. 6503:582-587. <https://doi.org/10.1126/science.abb9263>. **PDAID**
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- Gu, Wei, Xianding Deng, Kevin Reyes, Elaine Hsu, Candace Wang, Alicia Sotomayor-Gonzalez, Scot Federman, et al. 2020. "Associations of Early COVID-19 Cases in San Francisco With Domestic and International Travel." *Clinical Infectious Diseases* 71, no. 11:2976-2980. <https://doi.org/10.1093/cid/ciaa599>. **PDAID**
- Junqueira, Dennis Maletich, Dennis Maletich Junqueira, Eduan Wilkinson, Ana Vallari, Xianding Deng, Asmeeta Achari, Guixia Yu, Carole McArthur, et al. 2020. "New Genomes from the Congo Basin Expand History of CRF01\_AE Origin and Dissemination." *AIDS Research and Human Retroviruses* 36, no. 7:574-582. <http://doi.org/10.1089/aid.2020.0031>. **PDAID**
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- Shah, Sachin J., Peter N. Barish, Priya A. Prasad, Amy Kistler, Norma Neff, Jack Kamm, Lucy M. Li, Charles Y. Chiu, et al. 2020. "Clinical features, diagnostics, and outcomes of patients presenting with acute respiratory illness: A retrospective cohort study of patients with and without COVID-19." *EClinicalMedicine* 27, 100518. <https://doi.org/10.1016/j.eclinm.2020.100518>. **PDAID**
- Tan, Susanna K., Andrea C. Granados, Jerome Bouquet, Yana Emmy Hoy-Schulz, Lauri Green, Scot Federman, Doug Stryke, et al. 2020. "Metagenomic sequencing of stool samples in Bangladeshi infants: virome association with poliovirus shedding after oral poliovirus vaccination." *Scientific Reports* 10, no. 15392. <https://doi.org/10.1038/s41598-020-71791-4>. **PDAID**
- Greenfield, Sheldon, Edward M. Uchio, Mark S. Litwin, Gregory Gin, Isla Garraway, Timothy J. Daskivich, Harwood Garland, Sherrie H. Kaplan. 2020. "The Personalized Medicine for Prostate Cancer (PMPC) Study: The Role of Race, Genomics, and Patient Complexity in Treatment Outcomes." *Journal of Clinical Oncology* 38, no. 6, suppl. 32. [https://doi.org/10.1200/JCO.2020.38.6\\_suppl.302](https://doi.org/10.1200/JCO.2020.38.6_suppl.302). **Early Prostate Cancer: Predicting Treatment Response**
- Grover, Abhinav, Sheldon Greenfield, Sherrie Kaplan, Robert Stevenson, Edward Uchio. 2020. "14P Pharmacogenomic Signature for Dasatinib Response in Prostate Cancer: A Precision Medicine Initiative." *Annals of Oncology* 31, no. 1, suppl. 5: S1221. <https://doi.org/10.1016/j.annonc.2020.08.2173>. **Early Prostate Cancer: Predicting Treatment Response**
- Grover, Abhinav, Sheldon Greenfield, Sherrie



- Kaplan, Robert Stevenson, Edward Uchio. 2020. "34P Pharmacogenomics of Docetaxel Response in Prostate Cancer: A Precision Medicine Initiative." *Annals of Oncology* 31, no. 1, suppl. 1: S12. <https://doi.org/10.1016/j.annonc.2020.01.036>. **Early Prostate Cancer: Predicting Treatment Response**
- Hoffman, Karen E., David F. Penson, Zhiguo Zhao, Li-Ching Huang, Ralph Conwill, Aaron A. Laviana, Daniel D. Joyce, et al. 2020. "Patient-Reported Outcomes Through 5 Years for Active Surveillance, Surgery, Brachytherapy, or External Beam Radiation With or Without Androgen Deprivation Therapy for Localized Prostate Cancer." *JAMA* 323, no. 2: 149-163. <https://doi.org/10.1001/jama.2019.20675>. **Early Prostate Cancer: Predicting Treatment Response**
- Huelster, Heather L., Aaron A. Laviana, Daniel D. Joyce, Li-Ching Huang, Zhiguo Zhao, Tatsuki Koyama, Karen E. Hoffman, et al. 2020. "Radiotherapy After Radical Prostatectomy: Effect of Timing of Postprostatectomy Radiation on Functional Outcomes." *Urologic Oncology* 38, no. 12: 930.e23-930.e32. <https://doi.org/10.1016/j.urolonc.2020.06.022>. **Early Prostate Cancer: Predicting Treatment Response**
- Laviana, Aaron A., Zhiguo Zhao, Li-Ching Huang, Tatsuki Koyama, Ralph Conwill, Karen Hoffman, Michael Goodman, et al. 2020. "Development and Internal Validation of a Web-based Tool to Predict Sexual, Urinary, and Bowel Function Longitudinally After Radiation Therapy, Surgery, or Observation." *European Urology* 78, no. 2: 248-255. <https://doi.org/10.1016/j.eururo.2020.02.007>. **Early Prostate Cancer: Predicting Treatment Response**
- Reisz, Peter A., Aaron A. Laviana, Zhiguo Zhao, Li-Ching Huang, Tatsuki Koyama, Ralph Conwill, Karen Hoffman, et al. 2020. "Assessing the Quality of Surgical Care for Clinically Localized Prostate Cancer: Results from the CEASAR Study." *Journal of Urology* 204, no. 6: 1236-1241. <https://doi.org/10.1097/JU.0000000000001198>. **Early Prostate Cancer: Predicting Treatment Response**
- Heft, Ilea E., Yulia Mostovoy, Michal Levy-Sakin, Walfred Ma, Aaron J. Stevens, Steven Pastor, Jennifer McCaffrey, Dario Boffelli, David I. Martin, Ming Xiao, Martin A. Kennedy, Pui-Yan Kwok, James M. Sikela. 2020. "The Driver of Extreme Human-Specific Olduvai Repeat Expansion Remains Highly Active in the Human Genome." *Genetics* 214, no. 1: 179-191. <https://doi.org/10.1534/genetics.119.302782>. **Full Genome Analysis to Guide Precision Medicine**
- Shieh, Joseph T., Monica Penon-Portmann, Karen H.Y. Wong, Michal Levy-Sakin, Michelle Verghese, Anne Slavotinek, Renata C. Gallagher, et al. 2020. "Application of Full Genome Analysis to Diagnose Rare Monogenic Disorders." *medRxiv*. <https://doi.org/10.1101/2020.10.22.20216531>. **Full Genome Analysis to Guide Precision Medicine**
- Wong, Karen H. Y., Walfred Ma, Chun-Yu Wei, Erh-Chan Yeh, Wan-Jia Lin, Elin H. F. Wang, Jen-Ping Su, et al. 2020. "Towards a Reference Genome that Captures Global Genetic Diversity." *Nature Communications* 11, no. 1: 1-11.

<https://doi.org/10.1038/s41467-020-19311-w>.

### **Full Genome Analysis to Guide Precision Medicine**

Fu, Win, Casey W. Johnson, Bhagya K. Wijayawardena, Michael P. Kowalski, Miranda Kheradmand, Jennifer E. Van Eyk. 2020. "A Plasma Sample Preparation for Mass Spectrometry using an Automated Workstation." *Journal of Visualized Experiments* 158, no. 1: e59842, <https://doi.org/10.3791/59842>. **Early Prediction of Major Adverse Cardiovascular Events Using Remote Monitoring (MACE)**

Fuller, Garth, Kelly Njune Mouapi, Sandy Jounq, Chrisandra Shufelt, Irene van den Broek, Mayra Lopez, Shivani Dhawan, Mitra Mastali, Brennan Spiegel, C. Noel Bairey Merz, Jennifer E. Van Eyk, Aaron Robinson. 2019 (published online in 2020). "Feasibility of Patient-Centric Remote Dried Blood Sampling: The Prediction, Risk, and Evaluation of Major Adverse Cardiac Events (PRE-MACE) Study." *Biodemography and Social Biology* 65, no. 4: 313-322. <https://doi.org/10.1080/19485565.2020.1765735>.

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Shufelt, Chrisandra L., Andy Kim, Sandy Jounq, Lili Barsky, Corey Arnold, Susan Cheng, Shivani Dhawan, Garth Fuller, William Speier, Mayra Lopez, Mitra Mastali, Kelly Mouapi, Irene van den Broek, Janet Wei, Brennan Spiegel, Jennifer E. Van Eyk, C. Noel Bairey-Merz. 2020. "Biometric and Psychometric Remote Monitoring Predicts Cardiovascular Risk Biomarkers in Ischemic Heart Disease." *Journal of the American Heart Association* 9, no. 18: e016023. <https://doi.org/10.1161/>

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Sundaraman, Niveda, James Go, Aaron E. Robinson, José M. Mato, Shelly C. Lu, Jennifer E. Van Eyk, Vidya Venkatraman. 2020. "PINE: An Automation Tool to Extract and Visualize Protein-Centric Functional Networks." *Journal of the American Society for Mass Spectrometry* 31, no. 7:1410-1421. <https://doi.org/10.1021/jasms.0c00032>. **MACE**

van den Broek, Irene, Mitra Mastali, Kelly Mouapi, Cory Bystrom, C. Noel Bairey Merz, Jennifer E. Van Eyk. 2020. "Quality Control and Outlier Detection of Targeted Mass Spectrometry Data from Multiplex Protein Panels." *Journal of Proteome Research* 19, no. 6: 2278-2293. <https://doi.org/10.1021/acs.jproteome.9b00854>. **MACE**

Zhang, Shenyang, Koen Raedschelders, Vidya Venkatraman, Lilith Huang, Ronald Holewinski, Qin Fu, Jennifer E. Van Eyk. 2020. "A Dual Workflow to Improve the Proteomic Coverage in Plasma Using Data-Independent Acquisition-MS." *Journal of Proteome Research* 19, no. 7: 2828-2837. <https://doi.org/10.1021/acs.jproteome.9b00607>. **MACE**

### **Presentations and Posters**

Beale, Holly C., Jacquelyn M. Roger, Matthew A. Cattle, Liam T. McKay, Katrina Learned, Geoff Lyle, Ellen T. Kephart, et al. 2020. "Determining accuracy of RNA sequencing data for gene expression profiling of single samples." Poster, Proceedings of the Annual Meeting of the American Association for Cancer Research 2020 80, no. 16:nr 5464. <https://doi.org/10.1158/1538-7445.AM2020-5464>. **CKCC**

Cheney, Allison R., Lauren M. Sanders, Lucas

- Seninge, Holly C. Beale, Ellen Towle Kephart, Jacob Pfeil, Katrina Learned, et al. 2020. "H3K27M gliomas are characterized by a stall in the epithelial-mesenchymal transition." Poster, *Proceedings of the Annual Meeting of the American Association for Cancer Research* 2020 80, no. 15:nr 6154. <https://doi.org/10.1158/1538-7445.AM2020-6154>. **CKCC**
- Haussler, David. 2020. "The Treehouse Childhood Cancer Initiative." Talk, *Proceedings of the AACR Special Conference on Advancing Precision Medicine Drug Development: Incorporation of Real-World Data and Other Novel Strategies* 26, no. 12:nr IA02. <https://doi.org/10.1158/1557-3265.ADVPRECMED20-IA02>. **CKCC**
- Haussler, David. 2020. "NGS Workflow Made More Accessible Through Technology And Automation." Talk, *Precision Medicine World Conference 2020*, Silicon Valley, CA, January 21-24. **CKCC**
- Chiu, Charles. 2020. "Understanding the Wuhan Coronavirus." Panelist, *Gladstones Institutes*, San Francisco, CA, February 6. **PDAID**
- Chiu, Charles. 2020. "LET SCIENCE LEAD: A Special Online Forum on COVID-19." Speaker, *WuXi AppTec Forum*, Virtual, February 25. **PDAID**
- Chiu, Charles. 2020. "SC19: NGS for Infectious Disease Diagnostics." Short Course Instructor, *Molecular Med TRI-CON Conference & Expo*, San Francisco, CA, March 2. **PDAID**
- Chiu, Charles. 2020. "COVID-19 Here and Now." Speaker, NCASM Online Programming, Virtual, August 19. **PDAID**
- Chiu, Charles. 2020. "COVID-19 Testing, Surveillance, and Diagnosis: Notes from a Disease Detective." Talk, *UCSF Medical Education Course: What's Next: COVID-19, Science, and the Public Health*, Virtual, October 28. **PDAID**
- Chiu, Charles. 2020. "COVID-19 Testing, Surveillance, and Diagnosis: Notes from a Disease Detective." Speaker, UCTV Stem Cell Channel, Virtual, October 28. **PDAID**
- Chiu, Charles. 2020. "Metagenomic and Host Response Sequencing for Diagnosis of Viral Infections." Speaker, *Pan American Society for Clinical Virology Webinar*, Virtual, December 12. **PDAID**
- Van Eyk, Jennifer E. 2020. "Proteomics and its Role in Physiology." Lecture Presentation, Inaugural Student Lectureship, Department of Physiology and Biophysics, University of Illinois at Chicago, Chicago, IL, February 28. **MACE**
- Van Eyk, Jennifer E. 2020. "Precision Health and Proteomics." Conference Presentation, *Pittcon 2020*, Chicago, IL, March 5. **MACE**
- Van Eyk, Jennifer E. 2020. "Precision Biomarkers." Webinar Presentation, Virtual Podium, Remote, May 1. **MACE**
- Van Eyk, Jennifer E. 2020. "Precision Medicine – The Analytical Pipeline Behind Patient Remote Blood Sampling." Symposium Presentation, *17th Symposium on the Practical Applications of Mass Spectrometry in the Biotechnology Industry (Mass Spec 2020)*, CASSS, Remote, September 16. **MACE**
- Van Eyk, Jennifer E. 2020. "Proteomics in Precision Health: Knowing More." Lecture Presentation, Genome Sciences Seminar, University of

- Washington, Remote, October 7. **MACE**
- Van Eyk, Jennifer E. 2020. "Personalized Medicine: Automated High Content Proteomics for Therapeutic Screening." Symposium Presentation, *CESI Symposium*, Remote, October 26-28. **MACE**
- Van Eyk, Jennifer E. 2020. "ISHR-NAS 2020 President Award." Lecture Presentation, *XXXVIII Annual Conference of the International Society for Heart Research North America Section*, Remote, December 7. **MACE**
- Press**
- Engleberth, Sarah. 2020. "Design, development, and pilot of a digital point-of-care tool in multiple sclerosis." *Neurodiem*, October 20. <https://www.neurodiem.co.nz/news/design-development-and-pilot-of-a-digital-point-of-care-tool-in-multiple-6ZwPzyyGNTU2gcrf4mzQ3e>. **Precision Medicine for Multiple Sclerosis: Making It Work**
- Slone Partners. 2020. "Tremendous Breakthroughs at the Intersection of Big Data and Precision Medicine are Changing our Lives." *Slone Partners Blog and Latest News*, September 15. <https://www.slonepartners.com/breakthroughs-at-the-intersection-big-data-precision-medicine-changing-lives/>. **Personal Mobile and Contextual Precision Medicine (PERCEPT)**
- Bai, Nina. 2020. "Why COVID-19 Means You Need a Flu Shot This Year." *UCSF News*, September 9. <https://www.ucsf.edu/news/2020/09/418406/why-covid-19-means-you-need-flu-shot-year>. **PDAID**
- Cumbers, John. 2020. "With Its Coronavirus Rapid Paper Test Strip, This CRISPR Startup Wants To Help Halt A Pandemic." *Forbes*, March 14. <https://www.forbes.com/sites/johncumbers/2020/03/14/with-its-coronavirus-rapid-paper-test-strip-this-crispr-startup-wants-to-help-halt-a-pandemic/>. **PDAID**
- Fimrite, Peter. 2020. "On the trail of the coronavirus: How scientists track the pathogen." *San Francisco Chronicle*, May 18. <https://www.sfchronicle.com/health/article/On-the-trail-of-the-coronavirus-How-scientists-15279273.php>. **PDAID**
- Governor's Office of Planning and Research. 2020. "State of California-Funded Research Advances Pandemic Response." Press Release, April 3. [https://opr.ca.gov/ciapm/docs/20200402-Chiu\\_Press\\_Release\\_COVID19.pdf](https://opr.ca.gov/ciapm/docs/20200402-Chiu_Press_Release_COVID19.pdf). **PDAID**
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## B. Outreach Efforts: CIAPM Representation at External Events

- January 7, Lawrence Berkeley National Laboratory Tour, Berkeley
- February 26, Tufts Medical Center, Health+ Studio, and ACEs Connection, *Balancing ACEs with HOPE Workshop*, Sacramento
- March 3, National Institute of Minority Health and Health Disparities, *10th Anniversary Scientific Symposium: Innovations to Promote Health Equity*, Virtual
- May 20, California Health in All Policies Task Force, *Equity in the COVID-19 Era*, Virtual
- June 9, ACEsConnection, *Adverse Childhood Experiences and Racial Trauma*, Virtual
- June 10, *Precision Medicine 2020: Hyperindividualized Treatments*, Virtual
- August 12–14, *Community Information Exchange Summit*, Virtual
- September 28, *Rural HEAL Initiative*, Virtual
- October 2, National Academies of Science, Engineering, and Medicine, *Framework for Equitable Allocation of COVID-19 Vaccine*, Virtual
- October 6, Health Leads, *Intentionally Integrating Equity into SDOH Interventions – Evaluation*, Virtual
- October 18–19, National Academy of Medicine, *Annual Meeting: Confronting Urgent Threats to Human Health & Society: COVID-19 and Climate Change*, Virtual
- October 21, UC San Francisco California Preterm Birth Initiative, *Communities as the Compass: When communities are the North Star, research drives meaningful change*, Virtual
- October 27, American Society of Human Genetics, *All of Us Educational Session*, Virtual



## C. Key Personnel in 2020

### OPR

Kate Gordon, Director; Senior Advisor to the Governor on Climate

Julianne McCall, Co-Director of CIAPM

Shannon Muir, Co-Director of CIAPM

Megan Varvais, Science Communication Specialist & Administrator

Ken McCullough, CCST Science & Technology Policy Fellow (December 2019 – September 2020)

April Booth, Policy Fellow (December 2019 – December 2020)

Aiyana Emigh Cortez, Policy Fellow (August 2020 – present)

Hyunsoo Gloria Kim, Policy Fellow (August 2020 – present)

### UC Davis

Chris Wang, Financial Officer (January 2018 – June 2020)

## D. Meeting Agendas

- ▶ May 12 & 15, 2020, California Precision Medicine Advisory Council Inaugural Meeting [Agenda](#)
- ▶ August 26 & 27, 2020, California Precision Medicine Advisory Council Summer Meeting [Agenda](#)
- ▶ August 28, 2020, CIAPM ACEs Expert Selection Committee Meeting [Agenda](#)
- ▶ November 10 & 20, 2020, California Precision Medicine Advisory Council Fall Meeting [Agenda](#)

## E. Advisory Council Member Bios

### Nadine Burke Harris, MD, MPH

Dr. Nadine Burke Harris is an award-winning physician, researcher and advocate dedicated to changing the way our society responds to one of the most serious, expensive and widespread public health crises of our time: childhood trauma. She was appointed as California's first-ever Surgeon General by Governor Gavin Newsom in January 2019. Her career has been dedicated to serving vulnerable communities and combating the root causes of health disparities.

Dr. Burke Harris founded the Center for Youth Wellness in one of San Francisco's most

underserved communities, Bayview-Hunters Point, an organization leading the effort to advance pediatric medicine, raise public awareness, and transform the way society responds to children exposed to Adverse Childhood Experiences (ACEs) and toxic stress. She also founded and led the Bay Area Research Consortium on Toxic Stress and Health, to advance scientific screening and treatment of toxic stress.

## Ysabel Duron

Ysabel Duron is the Founder/CEO of the California based Latino Cancer Institute working to eliminate the Latino cancer burden nationwide by driving equitable access, research and policy.

Duron was an award-winning TV journalist for 43 years in the San Francisco Bay Area and elsewhere, but stepped away in 2013 to continue her role as a patient advocate and voice for the Latino community.

A cancer survivor, she serves both on the Institutional Review Board of the National Institutes of Health *All of Us* Research Program, and most recently joined the Board of California Institute for Regenerative Medicine, a state taxpayer funded initiative to support stem cell research.

Duron was inducted into the National Association of Hispanic Journalists Hall of Fame in 2009, named one of the 25 most outstanding Hispanics in the Bay Area in 2005 and honored with the W.E.B. DuBois from the San Jose Chapter of the NAACP in 2011, amongst other honors that reflect her community engagement.

## Samar Muzzafar, MD, MPH

Dr. Samar Muzaffar is an assistant secretary at the California Health and Human Services Agency. Prior to her appointment she was a population health and health systems design consultant for Integrated Health Solutions LLC. Dr. Muzaffar previously served as chief medical officer at the Missouri Department of Social Services for Missouri's Medicaid program and was the Emergency Medical Services medical director at the Missouri Department of Health and Senior Services. She served as an adjunct instructor at Washington University's Brown School, and was a clinical instructor and clinical assistant professor at the University of Missouri - Columbia University Hospital. Dr. Muzaffar is a member of the American College of Preventive Medicine's Board of Regents and Health Systems Transformation Task Force, and the American Academy

of Pediatrics Institute for Healthy Childhood Weight TEAM UP Payer Advisory Board. She earned an MPH from Johns Hopkins University and an MD from the University of Missouri-Columbia School of Medicine.

### Clara Lajonchere, PhD (*Chair*)

Dr. Clara Lajonchere's background reflects a wide range of professional, clinical, and research activities across Central Nervous System disorders. She has spent her career on cross-cutting issues in psychiatric genetics and translational medicine. Through the Institute for Precision Health at UCLA, Dr. Lajonchere is working collaboratively with thought leaders across the state of California to advance precision medicine and improve outcomes for patients. Prior to UCLA, Dr. Lajonchere held faculty appointments at USC and Keck School of Medicine where she served as Director of the National Institutes of Health Center for Genomic and Phenomic Studies in Autism and conducted research on models for dissemination of scientific information to underserved populations, including the Latino community. She also served as VP of Clinical Programs for Autism Speaks for over a decade, where she oversaw a diverse portfolio of basic science and clinical programs. She currently consults for several tech start-ups in the autism space focused on AI, robotics, and targeted therapeutics.

### Oliver Keown, MD

Dr. Oliver Keown is a UK-trained physician, scientist and former policy advisor turned healthcare and medical technologies venture capital (VC) investor with Intuitive Ventures. Prior to joining Intuitive, he was a VC investor with GE Ventures, driving startup deal-flow in the Bay Area and beyond across healthtech, life science and medtech domains.

In past roles Dr. Keown has advised and supported a range of U.S. and international healthcare innovation projects across technology, policy, commercial, and academic fields. Early in his career he worked as a junior doctor in the UK National Healthcare Service across a variety of medical and surgical disciplines. He holds an MD and a bachelor's degree in Pharmacology from the University of Edinburgh, Scotland.

### Kenneth Kim, MD

Dr. Kenneth Kim received his MD from Harvard Medical School, completed a fellowship at the MIT Sloan School of Management, and received internal

medicine and allergy/immunology training at UCLA. He has served on the clinical faculty both at UCLA and UC Irvine for over 15 years. He has been a medical monitor, consultant, and investigator on over 600 clinical trials, having published over 30 research articles and 50 abstracts in peer-reviewed journals. He is a nationally recognized expert in the areas of early stage clinical research, ethnobridging drug development strategy, influenza challenge, mold allergy, and latex allergy.

He has founded numerous health care services businesses, including a 200+ employee clinical research organization that he transitioned to private equity. He is currently the medical director of Ark Clinical Research and a strategic investor in a variety of startups, while also maintaining a private allergy and asthma practice in Southern California.

## Yvonne Maldonado, MD

Dr. Yvonne (Bonnie) A. Maldonado is Professor in the Departments of Pediatrics and Epidemiology and Population Health, Chief of the Division of Infectious Diseases, and Senior Associate Dean for Faculty Development and Diversity at Stanford University School of Medicine. Her research activities have included the epidemiology and prevention of viral infections such as rotavirus, measles, mumps, rubella, polio and pediatric HIV infection. Her research is conducted internationally in Zimbabwe and Mexico, as well as in the United States. She has written over 200 articles in peer-reviewed journals, and 50 book chapters on these topics. In 1989, Dr. Maldonado received the Epidemic Intelligence Service Alumni Award from the Centers for Disease Control and Prevention, and she was inducted into the Multicultural Alumni Hall of Fame at Stanford University in 2001 and the Stanford Medical Alumni RISE (Reach, Inspire, Serve and Engage) award in 2018. She is a Fellow of the American Academy of Pediatrics, a member of the Society for Pediatric Research, the Pediatric Infectious Disease Society and the American Public Health Association. Dr. Maldonado has devoted substantial effort to teaching and training activities at Stanford University as well as in national and international settings. Throughout her career, she has invested heavily in her commitment to improving cultural and gender diversity at all levels.

## Fatima Muñoz, MD

Dr. Fatima Muñoz is the Director of the Department of Research and Health Promotion at San Ysidro Health (SYHealth), a high performing Federally Qualified Health Center (FQHC) providing care to over 105,000 patients throughout San Diego County. Dr. Muñoz completed her medical training in Mexico and earned an MPH from Universidad Autónoma de Baja California. She possesses over 15 years of clinical research experience working in health promotion programs and epidemiological research studies, specifically among underserved populations. Dr. Muñoz's expertise in public health issues spans both sides of the U.S.-Mexico border with emphasis in the elimination of health disparities. Her award winning research portfolio includes: chronic disease, HIV prevention and treatment, cervical and breast cancer, and the impact of bi-national access to care on health policy. Most recently, SYHealth was awarded the *All of Us* Research Program from the National Institutes of Health. It is only one of six FQHCs west of the Mississippi that is part of the *All of Us* program and Dr. Muñoz is the Principal Investigator for SYHealth. In this capacity, she and her team have been contributing to the development and implementation of the program for Spanish-speaking participants.

## Hakan Sakul, PhD

As Vice President and Head of Diagnostics, Dr. Hakan Sakul leads Pfizer's company-wide Diagnostics efforts. Dr. Sakul worked in the biotech industry in human genetics and statistical genetics fields early in his career before moving to Parke-Davis Pharmaceuticals to direct human genetics, statistical genetics and pharmacogenetics programs. Following the merger of Parke-Davis with Pfizer, he has held positions of increasing responsibility, including Director/ Site Head for Clinical Pharmacogenomics, Senior Director roles in Molecular Profiling and Translational Oncology, and most recently as Executive Director of Diagnostics. After receiving bachelor's and master's degrees from Ankara University in Turkey, and a PhD in Quantitative Genetics from the University of Minnesota as a Rotary Foundation Scholar, he conducted postdoctoral studies at the UC Davis. He is the author of over 30 refereed scientific articles as well as many other papers, abstracts, and book chapters. Dr. Sakul is keenly interested in diagnostics and related medical technologies to advance precision medicine for the improvement of individualized healthcare.



## Mary Anne Schultz, PhD, MBA, MSN, RN

Dr. Mary Anne Schultz is an accomplished Senior Executive and Consultant with more than 40 years of success across the nursing service, nursing education, informatics, and clinical and business intel venues. Her broad areas of expertise include data analysis, program evaluation, and evidence-based practices customized to a system's health care clients. Throughout her executive career, Dr. Schultz has held faculty and leadership positions within the California State University and University of California systems, and Schultz & Associates. Dr. Schultz is a Professor, Informaticist and former Chair for the Nursing Department at CSU San Bernardino. She holds a PhD in Nursing Systems and Economics from UCLA, an MBA from Claremont Graduate University, and a certificate in Health Informatics from UC Davis.

## Keith Yamamoto, PhD (*Vice Chair*)

Dr. Keith R. Yamamoto is Vice Chancellor for Science Policy and Strategy, and Director of Precision Medicine at UCSF. A UCSF researcher since 1973, he is a leader in determination of gene regulatory mechanisms. He has led or served on national committees focused on public and scientific policy, public understanding of science, science education, open science, and peer review. He chairs the Coalition for the Life Sciences and sits on the National Research Council Governing Board Executive Committee, the Board of Directors of Research!America, the Board of Directors of the Public Library of Science, the Governing Board of the California Institute for Regenerative Medicine, and the Advisory Board for Lawrence Berkeley National Laboratory. As Chair of the NAS Board on Life Sciences, he created the study committee that produced *Toward Precision Medicine*, which enunciated the precision medicine concept, and he helped lead efforts in the White House, Congress, California, and UCSF to implement it. He was elected to the National Academy of Sciences, the National Academy of Medicine, the American Academy of Arts and Sciences, and is a fellow of the American Association for the Advancement of Science.

## F. Advisory Council Guidelines

CALIFORNIA PRECISION MEDICINE ADVISORY COUNCIL GUIDELINES

Ratified 8/26/2020

### ARTICLE 1. Purpose of the Council

The purpose of the Precision Medicine Advisory Council (Council) is to advise and make recommendations to the Governor’s Office of Planning and Research (OPR) on matters related to the California Initiative to Advance Precision Medicine (CIAPM) (Gov. Code, §§ 65055 – 65059).

**ARTICLE 2. Membership of Council and Desired Qualifications**

The Council should consist of the following eleven members:

The Surgeon General of California, *ex officio*

The Secretary, or an Assistant Secretary, of the Health and Human Services Agency, *ex officio*

Seven members invited by the Governor’s Office of Planning and Research

One member recommended by the Senate Pro Tem and one member recommended by the Speaker of the Assembly

Members should be experts in precision medicine representing, for example, physicians, private industry, patient advocacy and community groups, regulatory affairs specialists, health insurance providers, public policy experts, venture capital communities, or academia in the areas of data science, bioinformatics, bioethics, the microbiome, metabolomics, genomics, community engagement, wearable devices, or other related fields.

All members serve at the pleasure of OPR.

Members may not select alternates or designees.

**ARTICLE 3. Council Organization**

Expected term of service of Council members may be as follows:

In the first year

Three members may be invited by OPR to serve a three-year term

One member may be invited by OPR to serve a two-year term

Three members may be invited by OPR to serve a one-year term

Both members recommended by the Legislature may be invited to serve a two-year term

Following the first year, all new terms may be three years.

Members should serve no more than six years total on the Council.

Members invited to fill vacancies should serve out the remainder of the position’s term.

Vacancies that occur should be filled within 90 days after the occurrence of the vacancy, and should be filled in the same manner in which the vacating member was invited.

The Council will elect a Chair and a Vice Chair for a one-year term. The Vice

Chair will be responsible for fulfilling the Chair's duties when the Chair is unavailable.

#### *Nominations*

Nominations do not need to be seconded.

A person can nominate himself or herself.

Nominations for Vice Chair will follow election of Chair.

#### *Nominee Statements*

Each nominee will have 2 minutes to make a statement to the Council prior to the first round of voting.

#### *Elections*

Elections will be conducted via secret ballot.

Election ballots may not be submitted via email.

In the event of a tie, the Council will have a new round of voting that includes all candidates. The new round will not be a runoff.

Quorum is achieved with seven Council members.

Six affirmative votes are needed for procedural motions to pass.

Ex officio members may vote and are counted toward quorum.

All motions that do not receive at least six affirmative votes during a meeting part are held open for 48 hours after that meeting part adjourns.

Council members who were not present at the time a motion was made may submit their votes for open motions up to 48 hours after that meeting part adjourns.

If a Council member cannot attend a meeting, they may, prior to a meeting, submit written comments that may be read aloud by staff during the meeting. Comments should be no longer than a half page per agenda item.

Council members who voted for a motion during a meeting may not change their vote via email.

Non-election votes submitted by email are subject to public posting.

Council members will be reimbursed for travel consistent with OPR's travel policies.

Any member of the Precision Medicine Advisory Council should be ineligible to apply for funding as a Principal Investigator from project grants during his or her term of service on the Council, and for one year immediately following his or her term of service on the Council.

The Council should meet at least four times annually in person and the meetings should be held in locations that allow stakeholders in different regions of

the state to participate.

#### **ARTICLE 4. Responsibilities**

Responsibilities of the Council may include but are not limited to:

Identifying and recommending research fields, total funding levels, timelines, and selection committee members for the RFP process, and expert project evaluators

Preparing for and attending Council meetings

Developing strategies to support sustainability of the Initiative, respond to changes in societal needs and opportunities, and stimulate adequate community engagement with CIAPM activities

Reviewing and providing feedback on documents including, but not limited to, annual legislative reports and project evaluation reports

### **G. Press Release**

Governor's Office of Planning and Research, 4/3/2020

**State of California-Funded Research Advances Pandemic Response**

**UCSF Researcher Dr. Charles Chiu leads Coronavirus tracking using techniques refined under grant from California Initiative to Advance Precision Medicine**

Sacramento, CA – A State of California grant recipient is using the techniques he refined and expanded under that grant to sequence viral genomes from hundreds of COVID-19 patients, informing health officials of how the virus is mutating and spreading around the world. Charles Chiu, MD, PhD, an infectious disease physician and professor of laboratory medicine at University of California San Francisco, received the grant funding from the California Initiative to Advance Precision Medicine (CIAPM) housed in the California Governor's Office of Planning and Research (OPR). Chiu conducted the research in collaboration with four other Universities of California, the Department of Public Health, several California-based companies, and other partners.

CIAPM funded Chiu's project, Precision Diagnosis of Acute Infectious Diseases, from 2015-2018. Just prior to receiving this award, his team developed a method of rapidly diagnosing thousands of disease agents in a single, minimally invasive test, known as metagenomic next generation sequencing. CIAPM funds helped Chiu and his team achieve the critical step of taking the test from the research laboratory into the clinic, and expanding its application

to more diseases, including pneumonia. In addition, during the project period, Chiu's team optimized the test for faster results, and certified the test for use at hospitals and clinics across the country.

"I am extremely grateful for the support that the State of California has given for my work in precision medicine," said Chiu, who also serves as Director of the UCSF-Abbott Viral Diagnostics and Discovery Center. "It showed foresight and prepared us to respond immediately to the current crisis with real-time genomic sequencing."

Now Dr. Chiu is building on that work. By sequencing viral genomes from COVID-19 patients, Chiu is providing public health officials with valuable information about the virus's transmission, which can identify the origin of an individual's illness and can help determine if interventions, such as stay-at-home orders, are slowing the spread of infection. Chiu's work will also help officials understand if the virus is becoming more dangerous and whether small differences between strains of the virus have distinctive effects on human health.

"California's response to the COVID-19 pandemic relies on a huge amount of research that's already begun, long before the current moment," said Kate Gordon, Director of OPR and Governor Newsom's Senior Advisor on Climate. "Dr. Chiu's research is a perfect example. With State funds programmed for the past several years through OPR's California Initiative to Advance Precision Medicine, Dr. Chiu has been able to create a system that has already strengthened and will continue to support State leaders' ability to keep Californians safe and healthy."

"During a pandemic, the right information delivered at the right time can save countless lives," said California Surgeon General Dr. Nadine Burke Harris, MD, MPH. "Dr. Chiu is at the frontlines of elevating our scientific understanding of this disease by developing critical tools to help get answers fast."

California established CIAPM to capitalize on the state's strengths in high-performance computing and biotechnology for the benefit of all Californians, especially those who are disadvantaged by health disparities. The program supports three ongoing projects and is planning future grants. The Advisory Council leading the Initiative includes California Surgeon General Dr. Nadine Burke Harris and California Health and Human Services Secretary Dr. Mark Ghaly, as well as other health experts. The Council will meet virtually in May.



## H. Rare Disease Caucus Informational Hearing Agenda

**Chairs:** Assemblymembers Rob Bonta, Brian Maienschein, Marie Waldron  
**Informational Hearing**

**Subject:** Rare Access During Covid and Beyond

**Wednesday, August 12, 2020**

**11:00am-12:00pm**

### **AGENDA**

#### **I. Introduction and Overview**

- i. Caucus Co-chairs

#### **II. Rare Disease and Precision Medicine**

- i. Julianne McCall, PhD, Co-Director of Precision Medicine, Governor's Office of Planning and Research

#### **III. Rare Disease Patient Voices**

- i. Whitney Carter, Rare Disease Patient
- ii. Jennifer Sills, Rare Disease Mom, Founder/President, CSNK2A1 Foundation

#### **IV. Innovation in Rare Disease - Biosimilars**

- i. Dr. Vibeke Strand, Adjunct Clinical Professor, Division of Immunology and Rheumatology, Stanford University School of Medicine
- ii. Dr. Sameer Awsare, Internal Medicine, Kaiser Permanente

#### **V. Public Comment**

#### **VI. Closing Remarks**

## I. ACEs RFP Expert Selection Committee Bios

Melissa T. Merrick, PhD (*Chair*)

**President & CEO, Prevent Child Abuse America**

**Areas of expertise: Child Abuse/Early Adversity Prevention**

Dr. Merrick has nearly 20 years of clinical, research, and leadership experience related to the etiology, course, and prevention of child abuse and neglect. She is currently the President and CEO of Prevent Child Abuse America, the nation's oldest nonprofit organization dedicated to the primary prevention of child abuse and neglect.

Previously, Dr. Merrick was a senior epidemiologist at the National Center for Injury Prevention and Control at the Centers for Disease Control and Pre-

vention (CDC), in Atlanta, and served on a detail in the Office of the Commissioner at the Children’s Bureau in the Administration for Children and Families. In partnership with the U.S. Department of Health and Human Services’ Office of Child Abuse and Neglect, she served as the lead scientist for the Adverse Childhood Experiences (ACE) study at CDC for 8 years. Dr. Merrick successfully leverages her clinical and research experiences to communicate and disseminate the critical public health importance of preventing early adversity to key stakeholders with diverse priorities, backgrounds, and knowledge, including legislators, business and civic leaders, and members of the academic and medical communities.

Dr. Merrick received her BA in Psychology, *magna cum laude*, from the University of Pennsylvania, and her master’s and doctoral degrees in Clinical Psychology from the San Diego State University/University of California, San Diego joint doctoral program in clinical psychology, where she served as a program coordinator for the San Diego site of the Longitudinal Studies on Child Abuse and Neglect Consortium. Dr. Merrick was a National Institutes of Health-funded postdoctoral fellow at the University of Miami Child Protection Team (CPT), where she was involved in a multi-site program of research that examined child maltreatment risk and protective factors in families evaluated by CPTs across the state of Florida.

Dr. Merrick is married and has two young children who keep her grounded, thankful, and hopeful for a brighter future for all children.

Saida Abdi, PhD, MSW, LICSW

**Assistant Professor of Social Work, University of Minnesota**

**Areas of expertise: Refugees, Trauma Systems Therapy, Resilience**

Dr. Saida Abdi is a Clinical Social Worker and an expert in refugee trauma and resilience. She has worked for more than 20 years with refugee youth and families in the diaspora. Her areas of focus include building individual, family, and community resilience, improving systems of care responsiveness to the needs of refugee and immigrant communities, trauma systems therapy, and culturally responsive interventions. She is the co-developer of Community Connect, a multidisciplinary team-based intervention that worked with youth up to the age of 24 years of age who are at risk for violence of any type. She is also the Primary Investigator of the project RAJO (Somali for hope) in Canada, funded by the Public Safety Agency in Canada to support positive outcomes for Soma-

li-Canadian youth. This 5-year, multi-million-dollar project will be evaluated to test the impact of the intervention on youth outcomes.

Dr. Abdi previously served for over 12 years as Associate Director for Community Relations of the Refugee Trauma and Resilience Center at Boston Children's Hospital and Adjunct Professor of Boston College. She earned her PhD in Sociology and Social Work and a master's degree in Social Work from Boston University and a second master's degree in Communications and Media Studies from Carleton University in Ottawa, Canada. She is the co-author of the recently published book, *Mental Health Practice with Immigrant and Refugee Youth: A Socioecological Framework* (APA, 2019).

Larissa Avilés-Santa, MD, MPH

**Director, Division of Clinical and Health Services Research, National Institute on Minority Health and Health Disparities**

**Areas of expertise: Latinx/Women's Health, Healthcare Systems**

Dr. Larissa Avilés-Santa is the Director of the Division of Clinical and Health Services Research at National Institute on Minority Health and Health Disparities (NIMHD) at the National Institutes of Health (NIH). In her current role, she works with her great team on fostering research aimed at improving health outcomes of health disparities populations within the context of healthcare systems.

Prior to joining NIMHD, she worked at the National Heart, Lung, and Blood Institute from 2006 to 2019 as the Project Director for the Hispanic Community Health Study/Study of Latinos. In addition, she has participated in multiple NIH-wide committees and working groups addressing minority health, diabetes mellitus and its complications, and women's health. In 2015, she founded the NIH Hispanic Health Research Scientific Interest Group.

She has coauthored multiple publications on different Hispanic health topics and is a frequent guest lecturer at academic and other scientific venues within and outside of the NIH. In 2017, Dr. Avilés-Santa was the field coordinator of the post-hurricanes Irma and María recovery of the health and social services of the entire country of Puerto Rico. She worked in this capacity during the first six and a half months of recovery work coordinated by the U.S. Health and Human Services Agency.

Dr. Avilés-Santa earned her medical degree from the University of Puerto Rico School of Medicine, and completed a residency in internal medicine at the

University Hospital in San Juan. She completed her fellowship in endocrinology at the University of Texas (UT) Southwestern Medical Center, where she joined the faculty of the Endocrine Division. She also earned a master's degree at the UT School of Public Health.

Zulfiqar A. Bhutta, PhD, MBBS

**Inaugural Robert Harding Chair in Global Child Health, The Hospital for Sick Children**

**Inaugural Ibn Sina Scholar in Global Child Health, The Hospital for Sick Children**

**Co-Director of the SickKids Centre for Global Child Health**

**Founding Director of the Centre of Excellence in Women and Child Health, Aga Khan University**

**Areas of expertise: Global Child/Community Health, Nutrition**

In addition to his leadership roles at the Hospital for Sick Children, the Sick-Kids Centre for Global Child Health, and Aga Khan University in Pakistan, Dr. Zulfiqar Bhutta holds adjunct professorships at several universities, including Johns Hopkins University and the London School of Hygiene & Tropical Medicine. Dr. Bhutta is a Distinguished National Professor of the Government of Pakistan, Co-Chair of the Maternal and Child Health Oversight Committee of the World Health Organization Eastern Mediterranean Region, Chairman of the Coalition of Centres in Global Child Health, Past President of the International Pediatric Association, and a leading voice for health professionals supporting integrated maternal, newborn, and child health globally.

Dr. Bhutta leads large research groups in Toronto, Karachi, and Nairobi with a special interest in scaling up evidence-based, community setting interventions and implementation of Reproductive, Maternal, Neonatal, Child, and Adolescent Health and Nutrition (RMNCAH&N) interventions in humanitarian contexts. His work with community health workers has influenced maternal and newborn outreach programs for marginalized populations internationally, and his group's work with the World Health Organization (WHO) and Partnership for Maternal and Newborn Child Health (PMNCH) is guiding global policy on essential interventions for women, children, and adolescents.

Dr. Bhutta obtained his MBBS from the University of Peshawar and his PhD from the Karolinska Institute. He is a Fellow of the Royal College of Physicians, the Royal College of Paediatrics and Child Health, and the Pakistan Academy of Sciences. He was recently awarded the honour of Fellow of the Royal Society

and honorary Fellow of the American Academy of Pediatrics. Among many honors, in 2016, Dr. Bhutta received the World Academy of Sciences 2016 prize in Medical Sciences.

Keith Dobson, PhD

**Professor of Clinical Psychology, University of Calgary**

**Areas of expertise: Psychological Interventions, Depression, Professional Ethics**

Dr. Keith Dobson is a professor of Clinical Psychology who leads University of Calgary's Depression Research Laboratory. His research interests are in Clinical Psychology, Cognitive Behavioural Therapy, depression, and stigma. Dr. Dobson also examined psychological approaches and treatments for adults in primary care with Adverse Childhood Experiences. Further, he has written about developments in professional psychology and ethics, and has been actively involved in organized psychology in Canada, including a term as President of the Canadian Psychological Association. Dr. Dobson is also a Principal Investigator for the Opening Minds program of the Mental Health Commission of Canada, with a focus on stigma reduction related to mental disorders in the workplace. His work has yielded more than 300 peer-reviewed published articles, 80 chapters, 17 books, and presentations in many parts of the world. He is a Past President of both the Academy of Cognitive Therapy and the International Association for Cognitive Psychotherapy. Among other awards, he has been given the Canadian Psychological Association's Award for Distinguished Contributions to the Profession of Psychology, the Donald O. Hebb Award for Distinguished Contributions to the Science of Psychology, and the Award for Distinguished Contributions to the International Development of Psychology. Dr. Dobson received a PhD and a master's degree in Psychology from the University of Western Ontario, London and a bachelor's degree in Psychology/Sociology from the University of Alberta, Edmonton.

Willarda Edwards, MD, MBA

**Internal Medicine Physician**

**Member of the Board of Trustees, American Medical Association**

**Areas of expertise: Health Equity, Trauma, Migrant Communities**

Dr. Willarda Edwards has been committed to organized medicine for over 30 years, holding prominent positions in local, state, and national associations.



She is Past President of the National Medical Association, MedChi, Baltimore City Medical Society, and Monumental City Medical Society. Putting patients first has been her mission in her 10-year tenure on the board of CRISP, the regional health information exchange network in Maryland and Washington, DC.

Joining American Medical Association (AMA) in 1994, Dr. Edwards was appointed to the inaugural governing council of the Women Physicians Congress and has served on reference committees, task forces and chaired the AMA Council on Constitution and Bylaws. Elected to the AMA Board of Trustees in 2016 and re-elected in 2020, Dr. Edwards demonstrates hard work, leadership skills, and consensus building. She chaired the Task Force on Health Equity, resulting in the establishment of the AMA Center on Health Equity.

After completing active duty in the Navy, Dr. Edwards founded an internal medicine practice in Baltimore, where she is the managing partner. She retired from the U.S. Navy Reserves at the rank of commander after 24 years of service. In addition to her busy private practice and AMA responsibilities, Dr. Edwards held senior management positions at the National Association for the Advancement of Colored People Health Advocacy Division and at the Sickle Cell Disease Association of America.

Dr. Edwards knows the balance needed in a physician's work life and the need to always be an advocate for patients in the delivery of quality care.

Dylan G. Gee, PhD

**Assistant Professor of Psychology and Psychiatry, Yale University**

**Areas of expertise: Child Development, Stress, Mental Health**

Dr. Dylan Gee directs the Clinical Affective Neuroscience and Development Laboratory at Yale University. She received her bachelor's degree in Psychological and Brain Studies from Dartmouth College and her PhD in Clinical Psychology from UCLA. Prior to joining the faculty at Yale, Dr. Gee completed her clinical internship and postdoctoral training at Weill Cornell Medical College. Her research focuses on child and adolescent mental health, with primary goals to delineate typical and atypical trajectories of brain development, elucidate how early adversity influences sensitive periods of development, and translate knowledge of the developing brain to optimize interventions for children and adolescents with anxiety and stress-related disorders. Dr. Gee's research is funded by the National Institutes of Health (NIH), the Brain &

Behavior Research Foundation, the Jacobs Foundation, and the American Psychological Association (APA). She has received broad recognition for her work, including a NIH Director's Early Independence Award, the Janet Taylor Spence Award for Transformative Early Career Contributions from the Association of Psychological Science, and the APA's Early Career Award for Outstanding Contributions to Children, Youth, and Families.

Jacob Ham, PhD

**Director of the Center for Child Trauma & Resilience, Icahn School of Medicine at Mount Sinai**

**Areas of expertise: Trauma, Child Development, Psychotherapy, Evaluation**

Dr. Jacob Ham is a Clinical Psychologist, Associate Professor in Psychiatry, and Director of the Center for Child Trauma and Resilience at the Icahn School of Medicine at Mount Sinai. He receives federal and local grants to create and advance trauma-informed practices throughout multiple service systems including education, foster care, health care, and criminal justice. His most recent fundings from Substance Abuse and Mental Health Services Administration, the NYC Department of Education, and the Manhattan District Attorney's office are being used to create a trauma-informed adolescent substance abuse recovery and prevention program, a complex trauma treatment program inside the Mount Sinai Health System, crime victims treatment centers, and trauma-informed community schools. He is a highly sought trainer and consultant on trauma-informed engagement and maintains an active clinical practice at Mount Sinai Beth Israel for children, families, and adults, with a particular focus on using moment-to-moment relationship-based interventions that enhance attachment to overcome trauma and improve mental health. He received his PhD at the University of Massachusetts Boston and completed an internship at Massachusetts General Hospital and a fellowship at Children's Hospital Boston, both of which were part of Harvard Medical School.

H. Eugene Hoyme, MD

**Medical Director of the Sanford Children's Genomic Medicine Consortium**

**Professor of Pediatrics and Medicine, University of Arizona**

**Senior Advisor in Genetics/Genomic Medicine, University of South Dakota**

**Sanford School of Medicine**

**Areas of expertise: Pediatric Genetics, Fetal Alcohol Syndrome**

Dr. Eugene Hoyme serves as Senior Advisor in Genetics/Genomic Medicine at Sanford Health, University of South Dakota Sanford School of Medicine, and University of Arizona Health Sciences. He also serves as Medical Director of the Sanford Children’s Genomic Medicine Consortium, a formal collaborative in pediatric precision medicine among ten major children’s hospitals. Previously, he functioned as Department Chair of Pediatrics at the Sanford School of Medicine, President of Sanford Research and Chief Academic Officer for Sanford Health. He has held academic and leadership posts at the Stanford University School of Medicine, Lucile Packard Children’s Hospital, and the University of Vermont College of Medicine.

He earned his bachelor’s degree *summa cum laude* from Augustana University in Sioux Falls and his MD from the University of Chicago Pritzker School of Medicine. He completed his residency in Pediatrics and Clinical Genetics fellowship training at UC San Diego. He is board certified in Pediatrics, Clinical Genetics, and Clinical Cytogenetics. His research focuses on Pediatric Genetics/Precision Medicine and Fetal Alcohol Syndrome Spectrum Disorders (FASD).

Dr. Hoyme is the recipient many awards in research, teaching, and mentorship, including: the Western Society for Pediatric Research’s Joseph W. St. Geme Jr. Education Award; the National Organization on Fetal Alcohol Syndrome Excellence Award; the American Academy of Pediatrics David W. Smith Education and Mentorship Award; and the Fetal Alcohol Spectrum Disorders Study Group’s Henry Rosett Award for Lifetime Contributions to FASD Research. Recently, he was first author of revised expert consensus diagnostic guidelines for FASD based on evaluation of over 10,000 children worldwide spanning more than 20 years.

Patricia Kerig, PhD

**Director of the Risk to Resilience Laboratory, University of Utah**

**Professor of Clinical Psychology, University of Utah**

**Co-Director of the Center for Trauma Recovery and Juvenile Justice, University of Utah**

**Areas of expertise: Trauma, Juvenile Justice, Developmental Psychopathology**

Dr. Patricia Kerig received her doctorate in Clinical Psychology from UC Berkeley with a specialization in children and families. She is currently a Professor in

the Clinical Psychology program at the University of Utah, where she directs the Risk to Resilience Laboratory. She also serves as the Editor in Chief of the *Journal of Traumatic Stress*. Dr. Kerig is an author of over 185 scholarly journal articles, books, chapters, and journal special issues devoted to understanding the developmental psychopathology of risk, recovery, and resilience among children, adolescents, and families coping with adversity in the context of a range of traumatic stressors, including childhood maltreatment, exposure to interparental conflict and violence, and intimate partner abuse. Her current program of research is focused on investigating the link between childhood trauma exposure and adolescent delinquency, with attention on potential underlying psychophysiological, cognitive, emotional, and interpersonal processes. She has a special interest in risk factors specific to traumatized girls in the justice system and the roles of intersectionality in regard to gender, race, class, and sexual minority status. Dr. Kerig is a Co-Director of the Center for Trauma Recovery and Juvenile Justice, a National Child Traumatic Stress Network center whose mission is to develop and disseminate trauma-informed assessment and intervention strategies to the systems that serve at-risk youth, while protecting staff from the potential adverse effects of secondary traumatic stress.

Liliana J. Lengua, PhD

**Director of the Center for Child and Family Well-Being, University of Washington**

**Maritz Family Professor of Psychology, University of Washington**

**Areas of expertise: Adversity, Stress, Child Social-Emotional Development**

Dr. Lilliana Lengua is a Child Clinical Psychologist studying the effects of stress and adversity on children, examining risk and protective factors that contribute to children's resilience or vulnerability. She examines children's neurobiological stress responses, temperament, coping, parenting, and family contexts as risk and protective factors that account for the effects of adversity on children's social, emotional, and academic well-being.

Dr. Lengua has been an investigator on several federally-funded projects examining the development of executive function, the effects of low income, neighborhood, family, and parenting on neurobiological systems of self-regulation, and their effects on preschool and preadolescent children's social, emotional and academic development, neighborhood, family and peer effects on adolescent substance use, and childhood risk factors for the emergence of adult mental health problems. Dr. Lengua is the author of over 100 published papers, and currently serves on the steering committee for the Centers for Disease Control-funded Washington State Essentials for Childhood Initiative. She has also collaborated with the Harvard Center for the Developing Child's Frontiers of Innovation, and served on the Board of Trustees for Neighborhood House, a nonprofit anti-poverty organization.

Lloyd Michener, MD

**Professor of Family Medicine & Community Health, Duke University School of Medicine**

**Areas of expertise: Community Engagement, Family Health, Equity**

Dr. Lloyd Michener serves as a Professor of Family Medicine and Community Health at Duke University School of Medicine, Clinical Professor at Duke University School of Nursing, and Adjunct Professor at University of North Carolina Gillings School of Public Health. He also serves as Chair of the Board of the Foundation for Health Leadership and Innovation and is a member of the National Academies of Medicine Workgroup on Assessing Meaningful Community Engagement.

He served as Director of the "Practical Playbook", with the support of



the deBeaumont Foundation, Centers for Disease Control, and U.S. Health Resources & Services Administration. In addition, he served as Chair of the Department of Community & Family Medicine at Duke for more than two decades and was the founding director of the Duke Center for Community Research.

Nationally, Dr. Michener has served as the founding Co-Chair of the Community Engagement Steering Committee for the Clinical and Translational Science Awards of the National Institutes of Health (NIH), and as President of the Association for Prevention, Teaching and Research (APTR). He has been a member of the National Academies Institute of Medicine Committee on Integrating Primary Care and Public Health, the Board of Directors of the Association of Academic Medical Colleges, and the NIH Council for Complementary and Alternative Medicine. Awards include Phi Beta Kappa, Alpha Omega Alpha, the Mead-Johnson Award from the American Academy of Family Physicians, and the Duncan Clark Award from APTR.

Dr. Michener is a graduate of Oberlin College, Harvard Medical School, and completed his residency and fellowship in Family Medicine at Duke.

Charles A. Nelson III, PhD

**Professor of Pediatrics and Neuroscience, Harvard Medical School**

**Professor of Psychology, Department of Psychiatry, Harvard Medical School**

**Professor of Education, Harvard Graduate School of Education**

**Richard David Scott Chair in Pediatric Developmental Medicine Research,  
Boston Children's Hospital**

**Director of Research, Division of Developmental Medicine, Boston Children's Hospital**

**Areas of expertise: Developmental Cognitive Neuroscience, Childhood Adversity**

Dr. Charles Nelson's research interests center on a variety of problems in Developmental Cognitive Neuroscience, including the development of social perception, developmental trajectories to autism, and the effects of early adversity on brain and behavioral development. He chaired the John D. and Catherine T. MacArthur Foundation Research Network on Early Experience and Brain Development and served on the National Academy of Sciences panels that wrote *From Neurons to Neighborhoods*, and *New Directions in Child Abuse and Neglect Research*. In total, Dr. Nelson has published over 400 peer-reviewed journal articles and book chapters, has edited eight books, and

written three books. He has received the Leon Eisenberg award from Harvard Medical School, an honorary doctorate from Bucharest University (Romania), and the Ruane Prize for Child and Adolescent Psychiatric Research from the Brain & Behavior Research Foundation. He was a resident fellow at the Rockefeller Foundation Bellagio Center (Italy) and has been elected to the American Academy of Arts and Sciences, the National Academy of Medicine, and the British Academy.

Kenneth S. Ramos, MD, PhD

**Alkek Chair of Medical Genetics, Texas A&M Institute of Biosciences and Technology**

**Professor of Translational Medicine, Texas A&M College of Medicine**

**Professor of Oncology, Houston Methodist Research Institute**

**Executive Director, Institute of Biosciences and Technology, Texas A&M University Health Science Center**

**Associate Vice President, Texas A&M Health**

**Assistant Vice Chancellor for Health Services, Texas A&M University System**

**Areas of expertise: Precision Medicine, Genomics, Clinical Pharmacology**

Dr. Kenneth Ramos is an accomplished physician-scientist and transformational leader, with designations in the National Academy of Sciences and National Academy of Medicine. He is recognized throughout the world for his scientific contributions in the areas of Genomics, Precision Medicine, and Toxicology.

With formal training in Pharmaceutical Sciences, Chemistry, Biochemistry, Pharmacology, and Medicine, Dr. Ramos is helping to steer the changing landscape of medicine and healthcare. He leads several translational, clinical, and educational programs that integrate diverse approaches to elucidate genomic mechanisms of disease. Dr. Ramos has provided academic, executive, administrative, and scientific leadership in Genetics and Genomic Medicine and Toxicology at several institutions, and over the course of his career has mentored numerous clinicians and scientists in medical, veterinary, and pharmaceutical practice. He is committed to initiatives that advance modern technological applications to improve quality of healthcare, reduce disease burden, and lower health-associated costs.

Dr. Ramos's research has paved the way for groundbreaking research on LINE-1 retroelements and their role in chromatin remodeling, DNA damage and repair, and genetic reprogramming. His group was the first to establish a

role for retinoblastoma proteins as master regulators of epigenetic silencing of LINE-1 and later characterized novel targets for regulation of cancer cells. He is currently examining the utility of circulating LINE-1 protein as prognostic and diagnostic biomarkers of lung cancer, which combined with imaging may improve precision for early cancer detection. This knowledge is being used to develop targeted therapies for lung cancer.

Arash Shaban-Nejad, PhD, MPH

**Assistant Professor, Center for Biomedical Informatics, University of Tennessee Health Science Center and Oak Ridge National Laboratory**

**Assistant Professor, Department of Pediatrics, University of Tennessee Health Science Center**

**Areas of expertise: Precision Medicine, ACEs, Big Data**

In addition to his work at the Center for Biomedical Informatics at the University of Tennessee Health Science Center (UTCHSC) and Oak Ridge National Laboratory (ORNL), Dr. Arash Shaban-Nejad is also an adjunct faculty at the Bredesen Center for Interdisciplinary Research and Graduate Education at the University of Tennessee, Knoxville. Before joining the faculty at UTHSC, he was a Postdoctoral Fellow of the McGill Clinical and Health Informatics Group at McGill University. Dr. Shaban-Nejad received his PhD and Master of Science in Computer Science from Concordia University, Montreal and Master of Public Health from UC Berkeley. He received additional training at the Harvard School of Public Health.

Dr. Shaban-Nejad's primary research interests are population health intelligence, precision health and medicine, epidemiologic surveillance, and big-data semantic analytics, using tools and techniques from Artificial Intelligence, Knowledge Representation, and the Semantic Web. Dr. Shaban-Nejad is an associate editor of *BMC Medical Informatics & Decision Making*, and a guest editor of *Nature Digital Medicine*, *Artificial Intelligence in Medicine*, and *IEEE Journal of Biomedical and Health Informatics*. His research has been supported by the Canada Institute for Health Research, National Institutes of Health, the Gates Foundation, Microsoft Research, and Memphis Research Consortium. Dr. Shaban-Nejad is the Co-Chair of Health Intelligence workshops, which has been an integral part of the Association for the Advancement of Artificial Intelligence annual conference since 2014.