



SYMPOSIUM AGENDA

All times are in Mountain Time | MDT UTC-06:00

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DAY 1 к	nowledge & Values: Medicine and Public Health			
9:00-9:15am	Larry Gold, PhD Welcome			
SESSION 1: FAIRI	NESS IN THE FACE OF BIOLOGY			
9:15-10am	Kathryn Paige Harden, PhD Why DNA Matters for Social Equality			
10:00-10:45am	Tobias Kollmann, MD, PhD			
	Why Do Newborns Die and What Can We Do About It? Shift focus from pathogen to host			
10:45-11:00am	Break			
SESSION 2: NOV 11:00-11:45am	EL APPROACHES TO TREATMENT OF DISEASE Scott MacDonnell, PhD Exploring Cardiovascular Physiology to Uncover Novel			
	Cell Derived Cardiomyocytes and Human Engineered Cardiac Tissues			
11:45-12:30am	Alan Russell, PhD			
	Muscle Adaptation Gone Wrong - How Duchenne and Becker Muscular Dystrophy Cause Amplified Muscle Damage Revealing a Novel Therapeutic Target			
12:30-1:30pm	Lunch			
SESSION 3: FAIR	NESS IN THE FACE OF CLIMATE CHANGE			
1:30-2:15pm	Ted Scambos, PhD			
	Antarctica and Sea Level Rise: We're In This Boat Together			
2:15pm-3pm	Leilani Raashida Henry, MA Navigating in the White World at the Bottom of the Earth			
3:00pm-3:15pm	Break			
SESSION 4: FAIRNESS IN THE FACE OF CULTURE				
3:15-4:00pm	James Robinson, PhD, MPH Pricing Drugs for Innovation and Affordability			
4:00pm-4:45pm	Tim Snyder, PhD Reflections on Health and Freedom			

4:45pm-5:00pm Closing Remarks

DAY 2 Knowledge & Values: Humans and Computers

9:00-9:15am	Larry Hunter, PhD
	Introduction

SESSION 5: UNTANGLING THE TANGLES: WHEN YOUR BRAIN FAILS YOU

9:15-10:00am	Roy Parker, PhD RNA Abnormalities in Human Diseases and How They Might Be Corrected			
10:00-10:45am	David Eisenberg, DPhil Structure-Based Discovery of Small Molecules that Disaggregate Tau Fibrils from Alzheimer's Disease			
10:45-11:00am	Break			
SESSION 6: THE DICHOTOMY OF KNOWING AND UNKNOWING WITHIN THE HUMAN/AI PARTNERSHIP				
11:00-11:45am	Melissa Haendel, PhD			
	If We Cannot Count Rare Disease Patients, They Will Not Count			
11:45am-1:00pm	Krzysztof Fidelis, PhD			
	The Theoretical Acceleration in Identification of Protein Structures Video: Using AI to Accelerate Scientific Discovery			
1:00-2:00pm	Lunch			
SESSION 7: SHARED VALUES ACROSS THE SPECTRUM OF HUMAN AND COMPUTER INTERACTION				
2:00-2:45pm	Rob Reich, PhD			
	Carbon versus Silicon: Professional Ethics			
2:45-3:30pm	Estelle Smith, PhD			

The Calamity Prayer: Computational Spiritual Support as a Whole-Human Centered Approach to Healing

3:30-4:30pm David Fajgenbaum, MD, MBA Chasing My Cure: Lessons learned as a physician-researcherpatient-advocate

4:30-4:45pm Closing Remarks



WELCOME FROM LARRY

Wow, we are still here, as is the world, which is a good thing to be able to say. I read some of the past "welcome letters" and did some thinking about the raw pleasure of seeing so many old friends again, or at least being with you virtually. At a time that minor miracles are the best we can have, today is at least a step that makes me smile, gently. Please enjoy the talks and the discussions. One previous welcome letter said "Perhaps our odd blend of science and a deep, shared human need will do some good" – that remains today, more than ever, the goal, and maybe the primary goal of these events. From once thinking we could teach people biology to now bathing in our shared learning, our goals have become simpler.

We have learned to hold a "slightly enhanced view of the places that health care struggles. Our real goal, as we now understand it, is to lessen the struggles that harm us." During our more than a decade together we have seen (duh...) the obvious connections between health care and human behavior – being human is a burden and an opportunity, and even E. O. Wilson, a hero of mine who recently died, preferred being human to the far more orderly life of an ant or a bee.

By this weekend we will have had almost 200 speakers at these symposia, and the event continues to evolve. We had started, several years ago, to emphasize biology and policy, and now (perhaps for the next decade) we have centered on biology and big data. Biology plus big data are policy, after all. In the larger world, policy is about scale, and nothing can surprise us more than when our policies fail us. Tim Snyder, another hero, will speak today (and has written powerfully but shockingly calmly) about massive social failures. Life continues to pit power against power, rather than lift all of us toward our better, non-Darwinian selves. Robert Wright, an old friend, wrote in the *Moral Animal* about the difficulties of rising above Darwin. We can aim no higher!

This year Meredith and I invited Larry Hunter to complete our little triangle. He accepted our offer to be a permanent codirector of these events, after being so thoughtful last year as we tackled the big data topic. We are grateful for Larry's instincts and his remarkably integrated brain. He is also very funny, an irreplaceable quality.

As Watson and Crick famously wrote in 1953, it has not escaped our attention...that succession planning is always important and we have done that with Larry Hunter. As a now 80 year old, I look forward to a slow descent into a nice rocking chair at future symposia....with ever increasing gratitude.

Larry Gold



WELCOME FROM THE OTHER LARRY

As the long-time "other Larry," I am delighted to accept Larry and Meredith's invitation to join with them as a co-organizer. For more than a decade now, this symposium has been the highlight of my year. I revel in the fascinating ideas, great science, and, most importantly, the wonderful community Larry has created. I look forward to helping shepherd the next decade of our shared learning together as we navigate the growing convergence of biology, health, and data.

Coming from decades of experience with artificial intelligence and machine learning, I hope to help this community appreciate how algorithms can be partners in digesting, understanding, and interpreting our ever-growing treasure trove of data about life. At the same time, we need to discuss how our values can be reflected in those algorithms so that together we might shape a healthier, happier, and more just existence for us all.

Echoing Larry's paraphrase of Watson and Crick, it has not escaped our attention that this pairing of Larrys suggests the potential for continuing the spirit of the symposium into the indefinite future. I welcome the opportunity to deepen my connection with all of you, and to continue to help blaze a path through the unknowns of life, mind, and community towards a better future.

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Larry Hunter



MODERATORS DAY 1



CHARLES R. MIDDLETON, PhD

President and Professor Emeritus, Roosevelt University

Charles Middleton served as chair of the board of trustees of the seven City Colleges of Chicago from 2015 to 2017. During his tenure, the Colleges completed a major transformation in their academic quality and program focus and scope. He successfully led the search for a new chancellor and strengthened board oversight of academic and student support programs while maintaining the fiscal integrity of the college system. As the immediate past president of Roosevelt University, serving from July 2002 through June 2015,

he led successful efforts to enhance the quality of student life and to hire a new generation of talented faculty members and administrators. His interests include developing campus leaders for the next generation. In that work, he serves as a Senior Advisor in the Fellows Program of the American Council on Education (ACE) where he works annually with six or seven mid-level college and university administrators to help prepare them for senior leadership positions in higher education.

Prior to his service as president, Dr. Middleton was a history professor and dean of the College of Arts and Sciences at the University of Colorado at Boulder; provost and vice president for academic affairs at Bowling Green State University; and vice chancellor for academic affairs at the University System of Maryland. He has been active as a university leader and involved in higher education governance organizations for many decades, including service on the board of the American Council on Education. His scholarly accomplishments earned him election as a fellow of Britain's Royal Historical Society.

Dr. Middleton is an advocate for LGBTQ equality and inclusion in all aspects of American life. In that role he has been active both locally and nationally in multiple organizations, serving on numerous not-for-profit boards, including the boards of PFLAG-National, the leading national organization of parents and families who advocate for inclusion, and of SAGEUSA, which advocates for and develops programs to assist LGBTQ elders nationally. He was inducted into the Gay and Lesbian Hall of Fame of the City of Chicago in 2006.

Dr. Middleton earned his AB with Honors in History from Florida State University and his MA and PhD in History from Duke University.





TIM HARRIS, PhD, DSC Biotechnology Consultant and Science Advisor

Tim Harris is a science and business leader with 45 years of experience guiding and leading laboratory work and scientists in a range of molecular research areas. He is presently a consultant to several Biotechnology companies focusing mainly on matters of science. From April 2019 until August 2021, Dr. Harris was Executive Vice President of Corporate Development at Repertoire Immune

Medicines, a Flagship Pioneering company and from August 2021 until April 2022 he was the Chief Scientific Advisor to the company. He is now a consultant for them. Dr. Harris is a molecular biologist, biochemist and geneticist. He was until December 2018, EVP R&D at Bioverativ (acquired by Sanofi in March of 2018) which he joined in March of 2017. He has been a consultant to several Biotechnology companies, most recently to Torque Therapeutics and Codiak Biosciences. He is a Venture Partner at SV Health Sciences Investors. In the latter role, he founded Caraway Therapeutics, a mitophagy company in 2016 and in 2019 he founded Catamaran Bio, a company developing NK cell therapeutics.

Before Bioverativ, Dr Harris was the SVP of Precision and Translational Medicine at Biogen. Until 2011, he was the Chief Technology Officer (CTO) and Director of the Advanced Technology Program (ATP) at SAIC-Frederick, Inc. in Maryland which operates the National Cancer Institute's leading center for cancer and AIDS research (now Frederick National Laboratory operated by Leidos Inc.,). He served as President and Chief Executive Officer (CEO) of Novasite Pharmaceuticals, and he founded SGX Pharmaceuticals in 1999 (formerly Structural Genomix), where he built the company to more than 130 employees, raised \$85M in capital, and generated more than \$20M in revenue during six years as CEO before it was sold to Eli Lilly. Before founding SGX, Dr. Harris was Senior Vice President, Research and Development at Sequana/Axys. He began his scientific career working on animal viruses such as foot & mouth disease and was one of the first molecular biologists in 1981 to join the UK Biotech company Celltech (now UCB Pharma). He subsequently spent nearly five years at Glaxo Group Research (now GSK) as Director of Biotechnology from 1989 to 1993. He has been on the board of both Dendreon and Opgen. He is currently on the Board of Directors of PhenoTX in Edinburgh and Chairman of the SAB of both Carraway Therapeutics and Catamaran Bio and an observer on the Board of both companies. He is a visiting Professor at Columbia University and has published over 100 peer reviewed Research papers.



MODERATORS DAY 1



MICHAEL J. JOYNER, MD Caywood Professor of Anesthesiology, Mayo Clinic

Michael J. Joyner is the Caywood Professor of Anesthesiology at Mayo Clinic, where he was named distinguished investigator in 2010. His interests include exercise physiology, blood pressure, metabolism, and transfusion practices. He has also explored the limits of reductionism in biomedical research.

Joyner attended the University of Arizona with residency training at Mayo Clinic. His lab has been funded by the National Institutes of Health since 1993, and former fellows have established independent research programs at leading institutions throughout the world. He has held leadership positions at Mayo, in the extramural research community, and with leading journals.



SCHEDULE DAY 1

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KATHRYN PAIGE HARDEN, PhD

Professor of Psychology at the University of Texas at Austin; Psychologist and Behavior Geneticist



ABSTRACT

Why DNA Matters for Social Equality

For several years now, scientists have shown that DNA makes us different in ways that matter: for our personalities, our health, and our educational and economic success. Presenting the research that led

to her book *The Genetic Lottery*, Kathryn Paige Harden introduces readers to the latest genetic science, dismantling dangerous ideas about racial superiority and challenging us to grapple with what equality really means in a world where people are born different. Weaving together personal stories with scientific evidence, Harden shows why our refusal to recognize the power of DNA perpetuates the myth of meritocracy, and argues that we must acknowledge the role of genetic luck if we are ever to create a fair society.

BIOGRAPHY

Kathryn Paige Harden is a tenured professor in the Department of Psychology at the University of Texas at Austin, where she leads the Developmental Behavior Genetics lab and co-directs the Texas Twin Project. She is the author of The Genetic Lottery: Why DNA Matters for Social Equality. She has published over 100 scientific articles on genetic influences on complex human behavior, including child cognitive development, academic achievement, risk-taking, mental health, sexual activity, and childbearing. Her research has been featured in popular media outlets such as the New York Times, Washington Post, The Atlantic, and Huffington Post. In 2017, she was honored with a prestigious national award from the American Psychological Association for her distinguished scientific contributions to the study of genetics and human individual differences. In addition to research, Dr. Harden teaches Introduction to Psychology in a synchronous massive online class format. She received her Ph.D. in Clinical Psychology from the University of Virginia and completed her clinical internship at McLean Hospital/Harvard Medical School before moving to Austin in 2009.

TOBIAS KOLLMANN, MD, PhD

Pediatric Infectious Diseases Physician; Head of Systems Vaccinology at Telethon Kids Institute at Perth Children's Hospital

ABSTRACT

Why Do Newborns Die and What Can We Do About It? Shift Focus From Pathogen to Host

Newborn death due to infection remains one of the biggest threats to life across the human life span and across the globe. Vaccination can save millions of lives every year, but vaccines given to newborns a) induce protection too late, and b) do not cover the many pathogens that can infect newborns. We need to change our approach to begin making a difference. Increasing the newborn's resilience to infection, i.e., focusing on the host rather than the pathogen, is one such alternative approach. For example, we have shown that the vaccine targeting tuberculosis (BCG) increases newborn resistance to a broad range of pathogens far beyond tuberculosis that are causing severe infection in newborns (sepsis). While supported by ample data, the dogmatic thinking amongst many vaccinologists ('one vaccine targeting one pathogen') is what stands in the way to make this pathogen-agnostic approach benefit all. Thus, the paradigm shift required now is to allow policy to be guided by data rather than dogma.

BIOGRAPHY

Tobias Kollmann is a professor of Systems Vaccinology at Telethon Kids Institute in Perth, Australia. He also is Director of Systems Immunology with the Human Vaccine Project, a global not-for-profit network aiming to decode the human immune system. His expertise centers around newborn infectious diseases, immune ontogeny and early life vaccine responses employing cutting edge technology and analytics to extract the most information out of the typically small biological samples obtainable in early life.

He previously served as Division Head for Pediatric Infectious Diseases at the University of British Columbia, BC Children's Hospital. Kollman completed his M.D. and Ph.D. at the Albert Einstein College of Medicine, Bronx NY, followed by a residency in pediatrics and fellowship in infectious diseases at the University of Washington, Seattle, WA.



SCOTT MACDONNELL, PhD

Associate Director of Cardiovascular, Fibrosis, & Renal Research at Regeneron Pharmaceuticals

A

ABSTRACT

Exploring Cardiovascular Physiology to Uncover Novel Therapeutic Strategies Using Human Inducible Pluripotent Stem Cell Derived Cardiomyocytes and Human Engineered Cardiac Tissues

Building more relevant human model systems to explore complex cardiovascular biology is essential as we work to uncover new therapeutic treatment options for heart failure. Dr. MacDonnell will share the rationale and development of human-based cardiac cellular and tissue model systems.

BIOGRAPHY

Scott MacDonnell currently works at Regeneron Pharmaceuticals in the department of Cardiovascular, Fibrosis, and Renal Disease. Previously, he worked for 8-years as a principal scientist at Boehringer Ingelheim within the department of CardioMetabolic Disease Research where his research focused on identifying novel therapeutic treatment options for chronic kidney disease, heart failure, and fibrosis.

MacDonnell completed a Postdoctoral fellowship at Temple University Medical School in the lab of Dr. Steve Houser. His fellowship research focused on identifying mechanisms responsible for the pathogenesis of heart failure. He obtained his undergraduate and master's degrees in Exercise Physiology from the University of Delaware and completed his doctoral work in Cardiovascular Physiology at Temple University in Philadelphia, PA.

ALAN RUSSELL, PhD

Co-Founder and Chief Scientific Officer at Edgewise Therapeutics

AB

ABSTRACT

Muscle Adaptation Gone Wrong – How Duchenne and Becker Muscular Dystrophy Cause Amplified Muscle Damage Revealing a Novel Therapeutic Target

The human body has evolved with an ability to rapidly adapt to physical challenges by allowing controlled injury and repair of skeletal muscle as a way to increase muscle size and strength. Different skeletal muscle fiber populations exhibit different thresholds for this type of remodeling with an aim towards maximizing the speed of adaptation while minimizing the potential for detrimental effects on existing function. In serious inherited muscle diseases such as Duchenne and Becker muscular dystrophy, loss or mutation of the supportive muscle protein dystrophin results in an amplification of adaptive injury processes and uncontrolled damage in response to normal daily activities. With time, this leads to fibrosis, muscle loss, disability, and early death from cardiac or respiratory muscle weakness.

In this presentation, Russell describes how muscle has evolved into two major fiber populations – fast and slow, and his thoughts on why one of these populations, the fast fibers, are more susceptible to injury. He will detail how loss of dystrophin amplifies activity-driven muscle injury and how the nature of this injury creates an opportunity for a novel medicine to improve muscle health in these devastating diseases. To evaluate how this therapeutic approach impacts muscle health, Russelll also describes how proteomic profiling can be leveraged to measure muscle injury signatures in Becker muscular dystrophy.

BIOGRAPHY

Alan Russell is the Co-Founder and Chief Scientific Officer of Edgewise Therapeutics, based in Boulder CO, dedicated to the discovery and development of novel medicines to treat Duchenne muscular dystrophy and other severe, inherited muscle diseases. Previously, Dr. Russell served at GlaxoSmithKline as VP and Head of the Muscle Metabolism Discovery Performance Unit, leading a broad discovery and development effort focused on patients for whom muscle function is compromised. Prior to this, he worked at Cytokinetics Inc. and is the co-inventor of Tirasemtiv and Reldesemtiv, direct muscle sensitizers in clinical trials for Amyotrophic Lateral Sclerosis (ALS).

Dr. Russell received a B.Pharm. in Pharmacy and Pharmacology and Ph.D. in Cell Biology and Gene Therapy from the University of Bath in the UK and Postdoctoral training at the Stanford University School of Medicine. He has been active in the discovery and development of medicines to improve skeletal muscle health for the last 20 years.

TED SCAMBOS, PhD

Senior Research Scientist, Earth Science and Observation Center, CIRES, University of Colorado Boulder



ABSTRACT

Antarctica and Sea Level Rise: We're In This Boat Together

Using satellite data of the polar ice caps allows CIRES to map these regions in new ways, and study the effects of climate change in Antarctica. This data has

witnessed the collapse of ice shelf areas and glacier acceleration in the Antarctic Peninsula, ice streams of the Ross Ice Shelf, and wind-snow interactions on the East Antarctic Plateau. A recent study used satellite thermal data to identify the coldest locations in Antarctica, and the processes that set their minimum winter temperatures.

In this presentation, Dr. Scambos will recount experiences from his expeditions to Antarctica from unique large dune features in the center of East Antarctica ("megadunes") to icebergs off the shore of the Antarctic Peninsula, and his work on developing instrumentation to try to better monitor and understand Antarctic climate and ocean circulation in areas of major change.

BIOGRAPHY

Ted Scambos is a Senior Research Scientist at the Earth Science and Observation Center, a part of the Cooperative Institute for Research in Environmental Sciences (CIRES) at the University of Colorado Boulder.

Dr. Scambos served as Lead Scientist at the National Snow and Ice Data Center (NSDIC) for 14 years. Prior to NSIDC, he worked at NASA's Goddard Space Flight Center studying Antarctica using satellite data. He has been on 21 expeditions to Antarctica and was part of an international scientific team that crossed Antarctica by tractor traverse in 2008-2009. Scambos holds a Masters degree from Virginia Polytechnic Institute and State University and a Ph.D. in geology from the University of Colorado at Boulder.

He is the author or co-author of more than 150 scientific articles on his research, with funding from NASA, NSF, and USGS. He lives with his wife Kari in Lafayette, Colorado, and has two adult sons, Alex and Ben.

LEILANI RAASHIDA HENRY, MA

Founder of Being & Living Enterprises, LTD; Author of The Call of Antartica

ABSTRACT

Navigating in a White World at the Bottom of the Earth

Leilani Raashida Henry is the author of the book The Call of Antarctica: Exploring and Protecting the World's Coldest Climate. She utilizes the diaries of her

father George W. Gibbs, Jr., the first person of African descent to set foot on the continent of Antarctica, to explore this beautiful and desolate part of the world. Leilani will talk about the expedition on which her father served (Admiral Byrd III), the continent itself, and its importance to the global environment.

BIOGRAPHY

Leilani Raashida Henry is a licensed Educational Kinesiologist with 25-years of experience in leadership consulting and coaching. Formerly Director of Training and Development with Jones Intercable, and an Organizational Development Specialist at Honeywell and Lockheed Martin, Leilani codesigned Honeywell's first companywide Diversity, Equity, and Inclusion (DEI) training.

Her book, The Call of Antarctica: Exploring and Protecting the World's Coldest Climate, launched October 2021. She also authored the Navigating Conflict chapter, in Springer's, Management and Leadership Skills for Medical Faculty. Leilani received a B.A. from Spelman College, in Atlanta and M.A. from St. Thomas University, in St. Paul, MN. She's been awarded a fellowship for her work in Organizational Development and dialogue from Regis University's Institute on the Common Good. Born in Hawaii and raised in Minnesota, She is Joyce Gibbs's daughter, resident of Charter House, and George W. Gibbs Jr.'s daughter, who was crew on Admiral Richard E. Byrd's III expedition that was headed to the South Pole.

JAMES ROBINSON, PhD, MPH

Professor of Health Policy and Management, Chair of Health Policy and Management Division, Leonard D. Schaeffer Endowed Chair of Health Economics and Policy, and Director of Berkeley Center for Health Technology at Berkeley School of Public Health

ABSTRACT

Pricing Drugs for Innovation and Affordability

Drug prices need to be high to finance research and development but low to ensure affordability and access. Attempts to balance these conflicting imperatives are bedeviled by scientific uncertainty as

to product effectiveness at the time of initial launch and the subsequent evolution of clinical evidence. The combination of multiple goals and scientific complexity creates one political firestorm after another, exemplified most recently by the accelerated FDA approval, budget-crushing manufacturer's price, restricted Medicare coverage decision, and broad physician rejection of Ahuhelm for Alzheimer's disease. In this presentation, Robinson describes how drug prices are negotiated by innovators and purchasers in the context of rapidly evolving scientific knowledge. He then describes a model of dynamic prices that adjust to changes in the evidence of a drug's safety and effectiveness, to be applied to products such as Ahuhelm that are launched through FDA's accelerated review and Medicare's conditional coverage pathways.

BIOGRAPHY

James Robinson is the Leonard D. Schaeffer Professor of Health Economics at the University of California at Berkeley. He serves on a variety of professional advisory boards and gives numerous invited speeches for pharmaceutical and technology firms, health insurance plans, hospitals, physician organizations, universities, and public agencies.

At Berkeley, Professor Robinson's research focuses on the biotechnology, medical device, insurance, and health care delivery sectors. He has published three books and 150 papers in peer-reviewed journals such as the *New England Journal of Medicine, JAMA*, and *Health Affairs.* He teaches classes on public policy, health insurance, and the economics of the life sciences industry.

TIM SNYDER, PhD

Levin Professor of History at Yale University; Author of five books include On Tyranny and The Road to Unfreedom

ABSTRACT

Reflections on Health and Freedom

In American politics, healthcare is the providence of the Left and freedom of the Right. But what if healthcare and freedom were indissolubly connected in a modern society? In this philosophical lecture grounded in a certain amount of personal experience,

Snyder will set to make a broad case that the future of freedom in the United States depends upon a rethinking of our common responsibility for health and welfare.

BIOGRAPHY

Timothy Snyder is the Richard C. Levin Professor of History and Global Affairs at Yale University and a permanent fellow at the Institute for Human Sciences in Vienna. His books include Marxism, and Modern Central Europe: The Reconstruction of Nations; Sketches from a Secret War; The Red Prince: The Secret Lives of a Habsburg Archduke; Bloodlands: Europe Between Hitler and Stalin; Thinking the Twentieth Century (with Tony Judt); Black Earth: The Holocaust as History and Warning; On Tyranny: Twenty Lessons from the Twentieth Century; Road to Unfreedom: Russia, Europe, America; and Our Malady: Lessons on Liberty from a Hospital Diary.

Snyder's work has appeared in forty languages and has received a number of prizes. He has appeared in documentaries, on network television, and in major films. His books have inspired poster campaigns and exhibitions, films, sculpture, a punk rock song, a rap song, a play, and an opera. His words are quoted in political demonstrations around the world. He is currently finishing a philosophical book about freedom.

MODERATORS DAY 2



SARAH BURGAMY, PsyD

Founder of PhoenixRISE

Sarah Burgamy is the founder of a private practice in Denver, Colorado, PhoenixRISE, with specialty offerings in identity development (considering intersections of target and non-target status identities), sexual minority competency as well as transgender and gender variant issues with children, adolescents, and adults. She has provided presentations and trainings in diverse professional settings, both on a local and national level in educational settings from preschools to colleges and universities, in healthcare settings such as the Colorado Children's Hospital, the University

of Colorado Anschutz Medical Campus, Denver Health, and the Department of Veterans Affairs in New Haven, CT, as well as in the public community sector for organizations such as Big Brothers Big Sisters, Colorado Department of Public Health and Environment (CDPHE), Parents Families and Friends of Lesbians and Gays (PFLAG), and The GLBT Center of Colorado. Dr. Burgamy has been interviewed/ featured in media coverage in *The Denver Post* series, *Transgender in Colorado*, and on the Denver based daytime program, *The Everyday Show* addressing the phenomenon of gender identity and expression in children.

Dr. Burgamy has previously instructed courses as an adjunct assistant professor at the University of Denver in the Psy.D. program and the International Disaster Psychology Master's program focused on arenas of development and culture, LGBTIQQ cultural competency, and cross cultural analysis.

Dr. Burgamy is the former Colorado representative to the Council of Representatives of the American Psychological Association (APA), a member of the APA Committee on Sexual Orientation and Gender Diversity, a past-president of the Colorado Psychological Association (CPA), and has previously served as the Diversity Division Chair of CPA. She has been a member of the Board of Directors for Urban Peak, a non-profit organization in Colorado serving youth experiencing homelessness or at risk of becoming homeless, since 2008.

SCHEDULE DAY 2



ROBIN DOWELL, DSc

Associate Professor in Molecular, Cellular and Developmental Biology and Computer Science at University of Colorado Boulder

Robin Dowell is an Associate Professor in Molecular, Cellular, and Developmental Biology and Computer Science at University of Colorado Boulder. Dr. Dowell is also co-founder of the Boulder biotech startup Arpeggio Biosciences and holds a patent for the assessment of transcription factor activity.

In the human genome, the majority of disease-associated mutations reside within regulatory regions, but how these mutations lead to disease is not well understood. To tackle this problem, Dr. Dowell uses computational biology and molecular genetics to decipher transcription regulation and the activity of transcription factors, the major drivers of regulation. In addition to pursuing translational research activities, Dr. Dowell is a dedicated educator focused on bringing bioinformatics and data science initiatives to the University of Colorado Boulder campus.

Dowell earned two bachelor's degrees (Computer Engineering and Genetics) from Texas A&M University, a D.Sc. in Biomedical Engineering from Washington University in St Louis, and did postdoctoral research at MIT. She is a member of the Linda Crnic Institute and a Boettcher Investigator.

Knowledge & Values: Humans and Computers

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10:00-10:45am	David Eisenberg, DPhil Structure-Based Discovery of Small Molecules that Disaggregate Tau Fibrils from Alzheimer's Disease				
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4:30-4:45pm	Closing Remarks				

ROY PARKER, PhD

Director of the BioFrontiers Institute, Distinguished Professor, and Cech-Leinwand Endowed Chair of Biochemistry at University of Colorado Boulder

ABSTRACT

RNA Abnormalities in Human Diseases and How They Might Be Corrected

RNA molecules, and their regulation, are central to the functioning of human cells. Moreover, abnormalities in RNA regulation can lead to human

disease. For example, in bone marrow failure diseases, such as dyskeratosis congenita, the telomerase RNA required for chromosome maintenance is abnormally degraded. Understanding this degradation mechanism has suggested possible therapies to reverse this process and provide treatment for this disease. Similarly, neurodegenerative diseases such as ALS and Alzheimer's disease involve alterations in proteins that regulate RNA, leading to RNA abnormalities in these diseases. Determining how RNA regulation is altered in these diseases is an important area of research, and determining how those alterations can be reversed may lead to new therapeutic approaches.

BIOGRAPHY

Roy Parker is an Investigator with the Howard Hughes Medical Institute; Executive Director, BioFrontiers Institute; Cech-Leinwand Endowed Chair of Biochemistry and Distinguished Professor at the University of Colorado Boulder. He has a joint appointment with the Department of Molecular, Cellular and Developmental Biology. His research focuses on the translation, localization and degradation of eukaryotic RNA, how cells regulate different steps in this process to modulate gene expression, and how alterations in RNA regulation lead to human disease.

He has served on, and chaired, the NIH CDF-1 study section, and co-organized the Nucleic Acids Gordon Conference (1997), the RNA Processing Meeting at CSHL (2001), and the 2004 FASEB Conference on Post-Transcriptional Control (2004). He is, or has been, on the editorial boards of MCB, Science, Cell, RNA, Nucleic Acids Research, and was an editor of the Journal of Cell Biology and eLife. He was the President of the RNA Society (2010). He is an elected Fellow of the American Academy of Arts & Sciences (2010) and Member of the National Academy of Sciences (2012). He received his Ph.D. from the University of California, San Francisco and completed his Postdoctoral work at the University of Massachusetts, Worcester.

DAVID EISENBERG, PhD

Paul D. Boyer Professor of Biochemistry and Molecular Biology at University of California Los Angeles

ABSTRACT

Failing the development of effective drugs for Alzheimer's disease (AD), millions are destined to die with dementia. AD is the consequence of neuronal death and brain atrophy associated with the aggregation of protein tau into fibrils.

This suggests that disaggregation of tau fibrils could be a therapeutic approach to AD. The capacity for the polyphenolic small molecule EGCG, abundant in green tea, to disaggregate tau and other amyloid fibrils has long been known, but EGCG has poor drug-like properties and fails to fully penetrate the brain. Here we have cryogenically trapped a high-energy intermediate of brain-extracted tau fibrils on the kinetic pathway to EGCG-induced disaggregation and have determined its cryoEM structure. The structure reveals that EGCG molecules stack in polar clefts between the paired helical protofilaments that pathologically define AD. Treating the EGCG binding position as a pharmacophore, we computationally screened thousands of drug-like compounds for compatibility for the pharmacophore, discovering several that experimentally disaggregate brain tau fibrils. This work suggests the potential of structure-based, small-molecule drug discovery for amyloid diseases, perhaps portending chemical interventions for Alzheimer's akin to those so effective for treating cancer and metabolic disorders.

BIOGRAPHY

David Eisenberg has been on the faculty of UCLA since 1969, now as the Paul D. Boyer Professor of Biochemistry and Molecular Biology and as Investigator of the Howard Hughes Medical Institute. Beginning in 1999, Eisenberg concentrated on studies of prions and proteins in the amyloid state.

As a Harvard undergraduate, Eisenberg studied with Professor John T. Edsall, one of the pioneers of protein chemistry, who oriented his life's work. As a Rhodes Scholar at Oxford, Eisenberg earned a DPhil in theoretical chemistry for study with Professor Charles Coulson on hydrogen bonding in ice. Returning to the United States, Eisenberg worked as a postdoctoral fellow at Princeton with Professor Walter Kauzmann, the discoverer of the hydrophobic interaction. Together they wrote a monograph, The Structure and Properties of Water, still in print after 51 years. In a second postdoctoral fellowship at the California Institute of Technology, Eisenberg learned X-ray crystallography from Professor Richard Dickerson (who later joined the UCLA Department of Chemistry & Biochemistry faculty in 1981).

Eisenberg is a member of several scholarly societies, including the US National Academy of Sciences, the American Academy of Arts and Sciences, the National Academy of Medicine, and the American Philosophical Society. He has received the Harvard Westheimer Medal, the UCLA Seaborg Medal, the Harvey International Prize in Human Health, the Bert and Natalie Vallee Award in Biomedical Science, the 2020 Passano Award and is an honorary fellow of Queen's College, Oxford.

MELISSA HAENDEL, PhD

Professor and Chief Research Informatics Officer and Marisco Chair in Data Science at University of Colorado Anschutz Medical Campus



ABSTRACT

If We Cannot Count Rare Disease Patients, They Will Not Count

The phenotypic, genetic, and environmental characteristics that define a given disease are established in different demographics, regions,

contexts, and databases. Different knowledge sources model the attributes of a disease and their relationships differently. For example, one resource may include the variant-to-disease association, whereas another records only the phenotypic features and their onset associated with the disease. Further, patients are an often underrecognized source of disease knowledge. As our collective knowledge advances, there is also a philosophical debate about what constitutes a disease, and when to "lump" or "split." Our analysis has revealed that prior estimates of the number of rare diseases, at ~7,000, dating back to the 1983 United States Orphan Drug Act, grossly underestimated the number by approximately 3,000 diseases. A rare disease harmonization initiative, Mondo, aims to reconcile rare disease knowledge globally. Patient-level characterization supports improved data sharing and disease definition. The end result is a suite of resources that can be used in diagnostic and discovery tools, where every patient will have an equal opportunity for a diagnosis no matter where they live.

BIOGRAPHY

Melissa Haendel is the Chief Research Informatics Officer at the University of Colorado Anschutz Medical School, and Director of the Center for Data to Health (CD2H). Her background is in molecular genetics, developmental biology, and toxicology as well as translational informatics, with a focus over the past decade on open science and semantic engineering.

Dr. Haendel's vision is to weave together healthcare systems, basic science research, and patient generated data through development of data integration technologies and innovative data capture strategies. Dr. Haendel's research has focused on integration of genotype-phenotype data to improve rare disease diagnosis and mechanism discovery.

KRZYSZTOF FIDELIS, PhD

Director, Protein Structure Prediction Center, University of California Davis



ABSTRACT

The Theoretical Acceleration in Identification of Protein Structures

Knowledge of protein structure significantly aids in the investigation of macromolecular function, interactions, and biochemical pathways. It also impacts our understanding of human disease, and the development of therapeutics.

Major developments in both modeling and experimental determination of protein structure are dramatically changing the landscape of structural biology. First, advances in the utilization of multiple sequence information using coevolution analysis and machine learning have led to major breakthroughs in modeling of protein structures. Second, progress in cryo-EM has facilitated the determination of high-accuracy structures for large proteins and complexes.

The CASP (Critical Assessment of Structure Prediction) initiative assumes that progress in any field depends on being able to accurately assess the strengths and weaknesses of current methods, and that in modeling, methods can only be effectively assessed when models are produced without knowledge of the answers, i.e. the corresponding experimental structures.

Results from the most recent edition of CASP show dramatic improvement in computing the three-dimensional structure of proteins from amino acid sequence, with many models rivaling experimental structures in accuracy. We will examine the recent breakthroughs through the lens of DeepMind, a research company behind the deep learning advancements, as presented by Demis Hassabis, the company's founder and CEO, and John Jumper, the lead of the AlphaFold2 project.

These results suggest that deep learning approaches will also be effective for a range of related structural biology applications, including macromolecular assemblies, ligand docking, alternative conformations, disordered states, interpretation of genetic variants, and protein design. In drug discovery, better ligand docking methods should speed up the identification of lead compounds, including drug repurposing opportunities.

BIOGRAPHY

Krzysztof Fidelis is Co-Founder (with John Moult, 1994) of the Critical Assessment of Structure Prediction initiative (CASP) to evaluate modeling methods in structural biology. He also heads the Protein Structure Prediction Center, first at Lawrence Livermore National Laboratory (1994-2005), and then at UC Davis (2005-present).

To help navigate through structure similarities in proteins, Krzysztof's group introduced the local structure descriptors, defined as amino acid-attached structure context. Their mid-level range of granularity allows for characterizing structure in "modules" that are small and common enough to be found in many proteins. The formalism was applied in several areas, including identification of structure similarity, fold recognition, enzyme-ligand interactions, and structure-function relationships.

Although the primary thrust of his research is in development of methods for structure modeling assessment, he has participated in several collaborations in applied modeling, for example producing the structural models for the Rad1 cell cycle checkpoint proteins, later confirmed by experiment.

Krzysztof's group has also used genome-wide yeast binding-site and microarray expression data to show the combinatorial nature of gene regulation. These results provided specific data on how binding sites may be combined to allow a large number of expression outcomes using relatively few transcription factors.



ROB REICH, PhD

Professor of Political Science, Director of the Center for Ethics in Society, and Co-Director of the Center on Philanthropy and Civil Society at Stanford University

ABSTRACT

Carbon Versus Silicon: Professional Ethics

The revolutions in biotechnology (CRISPR and genetic editing) and information technology (artificial intelligence) call into question nothing less than what it means to be human and the place of humans in the natural world. Rapid acceleration on the technological

frontier makes it less likely that democratic regulation will be up to the task of installing sensible guardrails so that these revolutions support rather than subvert human interests and democratic stability. As a result, we must look to professional norms within bioengineering and computer science to help steer us. Are these up to the task?

BIOGRAPHY

Rob Reich is a philosopher, the Director of Stanford University's Center for Ethics in Society, Co-Director of the Center on Philanthropy and Civil Society, and Associate Director of its new Institute for Human-Centered Artificial Intelligence. He is a leading thinker at the intersection of ethics and technology, the author of *Just Giving: Why Philanthropy is Failing Democracy and How It Can Do Better.* A former sixth grade teacher, he has won multiple teaching awards at Stanford. He helped to create the global movement #GivingTuesday and serves as chair of its board.

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ESTELLE SMITH, PhD

Postdoctoral Associate at CU Boulder in the Department of Information Science

ABSTRACT

The Calamity Prayer: Computational Spiritual Support as a Whole-Human Centered Approach to Healing

In the literature and practice of medicine, especially chronic, palliative, and end-of-life care, spirituality and spiritual care are known to be of fundamental importance to patients' wellbeing. Yet the healthcare institution is ill-equipped to provide affordable and equitable

access to sufficient spiritual and mental health care for all patients. With ever-rising rates of mental illness, overdose, and suicide in a world shattered by pandemic, war, and societal fragmentation, what can be done to support the spiritual healing-and moreover thriving-of both individuals and society?

In this talk, Dr. Smith will share a research path toward a more humane future, guided by the principle that sociotechnical systems (e.g., social media, online communities, medical software) should be intentionally designed to support spiritual wellbeing, healing, and connection. Couched within her personal experiences of lifelong mental illness and losing her mother to cancer in 2015, Dr. Smith will synthesize insights from her studies of both existing and prototypical systems for health support, especially focusing on CaringBridge.org (a nonprofit social media platform that offers free health journaling services to over 40 million users annually) and Reddit (an ecosystem of diverse topic-based online communities, with over 50 million users annually). Dr. Smith's work with CaringBridge provides an empirically-derived definition of spiritual support that can inspire a whole-human centered design approach. She will discuss how approaches from User Interface Design, Machine Learning, Artificial Intelligence, and Data Science offer promising new mechanisms for facilitating spiritual support, focusing on opportunities to: (1) engineer new models of delivery for evidence-based spiritual and mental health care; (2) encourage prosocial behaviors in online spaces where deeply held spiritual values may clash; and (3) augment community assets and capacities for connection and support. By explicitly honoring spirituality in the design of the online systems that now shape our social worlds, Estelle hopes to rebuild a virtual universe that can help humanity transform our collective calamity into collaboration, kindness, and care for all.

Content Warning: Talk includes discussion and personal disclosure of physical and mental illness, suicide, and death/dying.

BIOGRAPHY

Estelle Smith is a Postdoctoral Associate at the University of Colorado Boulder in the Department of Information Science. With an emphasis in Human-Computer Interaction and Social Computing, Smith completed her Ph.D. in Computer Science in the GroupLens Research Lab at the University of Minnesota in 2020.

Through industry and interdisciplinary partnerships with organizations like CaringBridge, the Wikimedia Foundation, and Reddit, Dr. Smith's research explores online systems, communities, and Data Science or Artificial Intelligence and Machine-Learning (AI/ML)-based mechanisms for improving mental and spiritual wellbeing during health crises. Her work has received three awards at prestigious computing venues, including the CHI and CSCW conferences. Dr. Smith employs a Human Centered Design approach that uses qualitative, quantitative, and mixed methods to evaluate stakeholders' values, needs, and behaviors, and to design future sociotechnical innovations that can support spiritual healing and flourishing, even in the face of life-critical illness.



DAVID FAJGENBAUM, MD, MBA, MSc

Assistant Professor of Medicine in Translational Medicine & Human Genetics at the University of Pennsylvania, Founding Director of the Center for Cytokine Storm Treatment & Laboratory, Associate Director, Patient Impact of the Penn Orphan Disease Center, and Co-Founder/President of the Castleman Disease Collaborative Network

ABSTRACT

Chasing My Cure: Lessons learned as a physicianresearcher-patient-advocate

David will share about his journey from fighting for survival against idiopathic multicentric Castleman disease (iMCD) during medical school to conducting research leveraging the SOMAscan proteomic platform and ultimately collaborating with dozens of physicians, researchers, and

patients to accelerate progress for Castleman disease patients worldwide. His presentation highlights the incredible power when patients, physicians, advocates, researchers, caregivers, biopharmaceutical companies, and drug regulators unite to leverage cutting-edge technologies and turn our hope into action.

At 25 years old, Fajgenbaum presented with life-threatening multi-organ dysfunction for an unknown cause. Without a diagnosis and no hope for survival, a priest read him his last rites. Fortunately, the diagnosis was made and multi-agent chemotherapy saved his life, but he went on to have multiple deadly relapses. When he learned about the limited research funding, lack of resources, no FDA approved treatments, and no drugs in development beyond anti-IL-6 therapy, he co-founded the Castleman Disease Collaborative Network (CDCN) in 2012. In parallel, he began searching for insights into the pathogenesis of iMCD and potential new treatment approaches. Combining omic technologies such as SOMAscan with single cell profiling, tissue immunostaining, and bioinformatic tools, Fajgenbaum has discovered novel predictive biomarkers of treatment response and novel treatment approaches, including one (an mTOR inhibitor) that is saving his life and others.

Through his roles as a Board member for the Reagan-Udall Foundation for the FDA and Co-Chair for the CURE Drug Repurposing Collaboratory, Fajgenbaum is also advancing drug repurposing to ensure that all currently FDA-approved drugs are utilized to treat all diseases that can benefit from them. Though incredible progress has been made chasing cures, important work remains to identify treatments for all patients suffering from incurable conditions and we hope attendees will join us in this work.

BIOGRAPHY

David Fajgenbaum is a physician-scientist at the University of Pennsylvania, Founding Director of the Center for Cvtokine Storm Treatment & Laboratory (CSTL), Associate Director of the Penn Orphan Disease Center, and Co-Founder & President of the Castleman Disease Collaborative Network (CDCN). He is also the national bestselling author of Chasing My Cure: A Doctor's Race to Turn Hope Into Action and a patient battling idiopathic multicentric Castleman disease (iMCD). He is in his longest remission ever thanks to a precision treatment that he identified, which had never been used before for iMCD. An authority on cytokine storms and their treatment, Fajgenbaum leads over 20 translational research studies including the CORONA Project, which is the world's largest effort to identify, track, and advance COVID-19 treatments.

Fajgenbaum has published scientific papers in high-impact journals such as the *New England Journal of Medicine, Journal of Clinical Investigation*, and *Lancet*. He currently serves on the Board of Directors for the Reagan-Udall Foundation for the FDA, Co-Chair of the Advisory Board for the CURE Drug Repurposing Collaboratory, and Co-Chair of the Scientific Advisory Board for the CDCN. Dr. Fajgenbaum earned a B.S. from Georgetown University, M.Sc from the University of Oxford, M.D. from the University of Pennsylvania, and MBA from The Wharton School.



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In The Genetic Lottery, Harden introduces readers to the latest genetic science, dismantling dangerous ideas about racial superiority and challenging us to grapple with what equality really means in a world where people are born different. Weaving together personal stories with scientific evidence, Harden shows why our refusal to recognize the power of DNA perpetuates the myth of meritocracy, and argues that we must acknowledge the role of genetic luck if we are ever to create a fair society.

Current Speaker

ChasingMyCure.com Amazon.com

NATIONAL BESTSELLER - The powerful memoir of a young doctor and former college athlete diagnosed with a rare disease who spearheaded the search for a cureand became a champion for a new approach to medical research.

Current Speaker

"An extraordinary memoir ... It belongs with Atul Gawande's writings and When Breath Becomes Air." – Adam Grant, New York Times bestselling author of Originals

> A Doctor's Race to Turn Hope into Action

> > A MEMOIN

David Fajgenbaum

ASING

THE CALL OF ANTARCTICA

EXPLORING AND PROTECTING EARTH'S COLDEST CONTINENT

LEILANI RAASHIDA HENRY

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Antarctica is the coldest, windiest, highest, driest, and most remote part of the world. It's the world's largest polar dessert. Antarctica is a true wilderness.

Author Leilani Raashida Henry, daughter of George W. Gibbs, Jr., the first person of African descent to go to Antarctica, recounts her father's expedition while educating readers on the incredible geography, biodiversity, and history of the continent. Using diary entries from Gibbs' expedition, The Call of Antarctica takes readers on a journey to the rugged Antarctic landscape to learn its history, its present, and the importance of protecting its future.

Current Speaker



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TWENTY LESSONS FROM THE TWENTIETH CENTURY

TIMOTHY SNYDER

The Founding Fathers tried to protect us from the threat they knew, the tyranny that overcame ancient democracy. Today, our political order faces new threats, not unlike the totalitarianism of the twentieth century. We are no wiser than the Europeans who saw democracy

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TIMOTHY

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ON TYRANNY

yield to fascism, Nazism, or communism. Our one advantage is that we might learn from their experience. On Tyranny is a call to arms and a guide to resistance, with invaluable ideas for how we can preserve our freedoms in the uncertain years to come.

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In this forceful and unsparing work of contemporary history, based on vast research as well as personal reporting, Snyder goes beyond the headlines to expose the true nature of the threat to democracy and law. To understand the challenge is to see, and perhaps renew, the fundamental political virtues offered by tradition and demanded by the future. By revealing the stark choices before us--between equality or oligarchy, individuality or totality, truth and falsehood--Snyder restores our understanding of the basis of our way of life, offering a way forward in a time of terrible uncertainty.

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FROM HORROR TO HOPE

Recognizing and Preventing the Health Impacts of War

BARRY S. LEVY

From Horror to Hope documents the health consequences of war, primarily for noncombatant civilians but also for military personnel and veterans, and outlines what can be done to reduce these consequences. Written by a public health physician engaged with this subject for decades, the book also describes positive developments in addressing the health impacts of war. In addition, the book profiles inspiring health professionals who are providing healthcare for war-affected populations and participating in education, research, and advocacy to reduce the health impacts of war. And the book demonstrates how traditional public health frameworks and new paradigms can be applied to the prevention of war and the promotion of peace.

Former Speaker



SAVE THE DATE



14TH ANNUAL GOLDLAB SYMPOSIUM May 18-19, 2023

ABOUT THE COVER ART

Alliance is a piece of machine-sewn thread on paper. Yellow and Blue threads march toward the center of the piece from opposite sides, approaching a gap between them. They cross the ravine and sweep an arc through the other's territory before turning back toward their original side. These threads relate to one another by color, proximity, movement, and shared ground. They work together; sometimes parallel, sometimes across a chasm. They overlap, they diverge and converge, conflict with one another, complement one another.

The piece as a whole could be seen as two sides conversing – as two hemispheres of the brain and their corpus callosum. Or, alternately, as a whole social fabric, a tapestry ecosystem of threads; parts and players. Perhaps it mimics a multitude of undulating waves, the effect of a droplet into a liquid surface. This piece was conceived after a conversation with Larry Gold and Larry Hunter about this year's Symposium's emphasis on the necessity for shared values across the spectrum of Human and Computer interaction. I felt compelled by the seeming dichotomy of knowing and unknowing within this world of Human/AI partnership. The process of learning from one another is a perpetual cycle of identifying what we know and what we don't. A back-and-forth, a co-existence that stands to be enhanced by our experience of or with the other.

DARIN GRASSMAN

Darin Grassman is an artist and designer based in Colorado. Her work spans a range of media, though is largely influenced by the world of print, including analog, digital, and 3D. She holds a BFA in Painting and an MA in Printed Textiles, though has worked primarily in binderies and print shops. After working in commercial bookbinding for several years, she started LA Bookmaker, a company that sells short-run stationery and creative office supplies.

dgrassman.com la-bookmaker.com

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