

Program Book

2019
NF Conference

SEPTEMBER 21-24, 2019
HYATT REGENCY
SAN FRANCISCO, CA

CHILDREN'S
TUMOR
FOUNDATION
ENDING NF
THROUGH RESEARCH

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DOWNLOAD THE 2019 NF CONFERENCE MOBILE APPLICATION

The app is available for iPhone, iPad, Blackberry and Android devices and will enable you to consult the latest news on the event, read about the sessions, network with colleagues, plan your visit, and much more!



WIFI NETWORK

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Password: nfconference (all lower case)

Dear NF Conference and NF Forum Attendees:

On behalf of the Children's Tumor Foundation, I welcome you to the 2019 NF Conference and NF Forum in beautiful San Francisco, California. It is an honor and inspiration to bring the entire NF community together so that scientists, clinicians, volunteers, donors, families, patients, and CTF staff members can mix and mingle, learn from each other, and make this weekend incredibly special.

If you were to ask me: what would make you the most grateful at this year's NF Conference and Forum? The answer would be very simple: to grow our CTF family even more.

We are tremendously pleased to have as our opening keynote speaker Dr. Stephen Groft, Director of the NIH's Office of Rare Diseases Research – an absolute guru in the rare disease space!

Our dedicated NF Conference Chairs Allan Belzberg, Juha Peltonen and Jill Weimer, together with our conference director Patrice Pancza, were able to attract some indisputable talent this year. It is exciting to note that keynote speakers from outside the NF community will be with us, including Lloyd Minor, MD, Dean of the Stanford University School of Medicine; Allan Basbaum PhD, FRS, Professor and Chair, Department of Anatomy, University of California, San Francisco; and Heike Daldrup-Link, MD, PhD, Department of Radiology, Stanford University. They enthusiastically accepted our request to come to the conference and share their expert views on the fields of cancer, pain, and imaging.

This year's NF Forum will offer an impressive program to educate and empower patients, families, and caregivers. Over the past year, CTF engaged with the European Patient Forum in a project around patient engagement (PARADIGM) and the lead of this project, Mathieu Boudes, PhD, will present at the NF Forum.

The astonishing NF Forum Chairs Dave Viskochil, Andrea Gross, Onno Faber, Maureen Hussey and Jessica Sambalnet, together with our Director of Patient Engagement Traceann Rose, drew wonderful experts, many of them also new to the NF community. Stefan Friedrichsdorf, MD, the Medical Director of the Department of Pain Medicine, Palliative Care and Integrative Medicine at Children's Minnesota, Minneapolis-St. Paul, will present on the important topic of NF and pain. The Forum will also include a panel discussion on drug development that will include a team of industry, medical professionals, and patients.

I truly hope that you will be able to join us at the combined Conference-Forum dinner on Saturday evening, where we are pleased to present a global panel of caregivers and patients who will talk about NF care around the world.

Last but not least, I wish you a few enriching, inspiring, and fun days. Enjoy the company of old friends, make some new friends, and celebrate each other's successes and discoveries. We will build upon the knowledge shared and the collaborations fostered this weekend, because only together can we end NF!



ANNETTE BAKKER

President and Chief Scientific Officer

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CHILDREN'S TUMOR FOUNDATION FUNDING OPPORTUNITIES IN 2020

YOUNG INVESTIGATOR AWARDS

The Children's Tumor Foundation has always striven to fund innovative NF research through its investigator-initiated award programs, namely the Young Investigator Award (YIA), Drug Discovery Initiative (DDI), Drug Discovery Initiative Registered Reports (DDIRR), and Clinical Research Award (CRA). **Towards this, we are very happy to announce that we have significantly increased the amount of funding for the YIA program for the upcoming 2020 cycle.** We expect that this increased allocation of funds will allow us to support several more early-stage researchers than we could in the recent past.

The YIA program will once again be expanded to include **all manifestations of all types of NF (NF1, NF2, schwannomatosis)**. Furthermore, a subset of the available funds will be dedicated exclusively to funding NF2 and schwannomatosis-focused studies, and such proposals will be evaluated separate from the NF1-focused proposals to ensure that at least a minimum number of NF2/schwannomatosis studies can be initiated. We hope that these changes will encourage all early-stage NF researchers, especially those interested in NF2 and schwannomatosis, to consider applying to the YIA program!

AWARD AMOUNTS:

Award amounts vary depending on pre-doc or post-doc status of the applicant and level of training. Please refer to our website <https://www.ctf.org/research/awards-applications> for more information.

IMPORTANT DATES TO NOTE

- **Monday, Dec. 9, 2019** - YIA Letter of Intent (LOI) form posted on ctf.org
- **Friday, Jan. 3, 2020** - YIA LOI's due by 5:00 pm EST
- **Friday, Jan. 24, 2020** - YIA invitation to full application
- **Friday, Mar. 6, 2020** - Full applications due by 5:00 pm EST
- **Week of May 18, 2020** - YIA decision notifications

DRUG DISCOVERY INITIATIVE REGISTERED REPORTS (DDIRR)

DDIRR Awards is a funder-publisher partnership that integrates the Registered Reports model in the grant application process. This model will allow for more rigorous, reproducible and transparent science, guaranteeing its awardees with an in-principle acceptance (IPA) to publication in the journal PLOS ONE, regardless of study outcome.

AWARD AMOUNTS:

up to \$40,000 for in-vitro studies
up to \$85,000 for in-vivo studies

IMPORTANT DATES TO NOTE

- **Monday, Sept. 23, 2019** - Letter of Intent (LOI) form posted on ctf.org
- **Monday, Oct. 21, 2019** - LOI's due by 5:00pm EST
- **Monday, Nov. 18, 2019** - Invitation to full application
- **Monday, Dec. 16, 2019** - Full proposals due by 5:00pm EST
- **March, 2020** - Decision Notifications

CLINICAL RESEARCH AWARDS

To accelerate NF research, CTF launched the Clinical Research Award (CRA) program in 2007 to support early stage pilot clinical trials of candidate therapeutics or interventions for treatment of manifestations of NF1, NF2 and schwannomatosis. In addition, these awards support innovative clinical trial enabling studies.

AWARD AMOUNTS:

Funding of up to \$150,000 is offered for these two-year awards.

IMPORTANT DATES TO NOTE

The next award cycle for CRAs will begin in the fall of 2020. Exact dates for submission of application materials will be provided on the ctf.org website shortly.

Please connect with any of the CTF staff for any questions. We look forward to receiving your applications!



The Friedrich von Recklinghausen Award: Neurofibromatosis Tradition and Progress

The Children's Tumor Foundation's Friedrich von Recklinghausen Award is given to individuals in the professional neurofibromatosis community who have made significant contributions to neurofibromatosis research or clinical care. It is named after Friedrich Daniel von Recklinghausen (1833-1910), the German physician who first described 'von Recklinghausen's disease' – what we now know as neurofibromatosis type 1.

2019 Friedrich von Recklinghausen Award Recipient



It is with great pleasure that the Children's Tumor Foundation announces the 2019 recipient of the Friedrich von Recklinghausen Award, Scott Plotkin, MD, PhD, Director of the Family Center for Neurofibromatosis at Massachusetts General Hospital and a Professor of Neurology at Harvard Medical School. This von Recklinghausen award marks the 10-year anniversary of the landmark study establishing the efficacy of bevacizumab for treatment in NF2, led by Dr. Plotkin and published in the New England Journal of Medicine in 2009. Dr. Plotkin has continued to improve treatment of patients with NF2 as an investigator on subsequent clinical trials of bevacizumab and other candidate therapeutics; as a co-PI of the Synodos for NF2 drug discovery program; and as co-founder of NF2 Therapeutics, Inc. Dr. Plotkin has also made major contributions to NF clinical trials as founder and Chair of the Director's Council for the Response Endpoints in Neurofibromatosis and Schwannomatosis (REINS) International Collaboration. Launched at the 2011 CTF NF Conference, REINS now consists of 150+ clinicians, researchers, and patient representatives working across 8 topical groups to standardize and improve clinical outcome measures for use in NF clinical trials.

Dr. Plotkin has demonstrated consistent leadership in the field through his service in numerous committees and conferences; he currently serves as chair of the CTF Clinical Care Advisory Board and co-chair of the International Collaboration for Revision of Diagnostic Criteria for Neurofibromatosis. Finally, this award recognizes the outstanding contributions Dr. Plotkin has made in mentoring new NF clinicians and researchers, many of whom have gone on to receive funding for new lines of NF research from CTF, the DOD, and other agencies.

Please join us in congratulating Dr. Plotkin for this well-deserved award!

The following are the most recent recipients of the Award:



2008
Vincent 'Vic' Riccardi, MD
The Neurofibromatosis Institute



2009
Luis Parada, PhD
University of Texas Southwestern



2010
Nancy Ratner, PhD
Cincinnati Children's Hospital
Medical Center



2012
David Gutmann, MD, PhD
Washington University



2013
Brigitte Widemann, MD
National Cancer Institute



2014
Gareth Evans, MD
St. Mary's Hospital,
University of Manchester, UK



2015
Eric Legius, MD, PhD
University of Leuven, Belgium



2016
David Viskochil, MD, PhD
University of Utah



2017
Karen Cichowski, PhD
Harvard Medical School

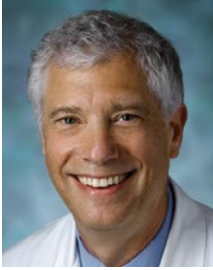


2018
Ludwine Messiaen, PhD
University of Alabama
at Birmingham

SCHEDULE

Schedule At-A-Glance

	TIME	EVENT	LOCATION
FRI 9/20	5:00 PM - 8:00 PM	Registration	Grand Ballroom Foyer
	5:00 PM - 10:00 PM	Poster Setup	Pacific H-O
SATURDAY SEPTEMBER 21	7:00 AM - 5:00 PM	Registration	Grand Ballroom Foyer
	7:30 AM - 12:00 PM	CLINICAL CARE SYMPOSIUM	Grand Ballroom
	12:45 PM - 1:00 PM	CONFERENCE KICK-OFF	Grand Ballroom
	1:00 PM - 2:00 PM	KEYNOTE 1: From Patients to Patients – And a Whole Lot In-Between	Grand Ballroom
	2:00 PM - 4:00 PM	SESSION 1: Natural History of Neurofibromatosis	Grand Ballroom
	4:00 PM - 4:30 PM	Break	Grand Ballroom Foyer
	4:30 PM - 5:35 PM	SESSION 2: Psychosocial Issues of the NF Patient	Grand Ballroom
	5:30 PM - 6:30 PM	Mentoring Session: "Speed-Dating with the Experts"	Seacliff AB
	6:30 PM - 7:30 PM	Reception and Special Poster Session for NF Forum Attendees - All Welcome	Pacific H-O
	7:45 PM - 9:45 PM	Welcome Dinner for NF Forum and NF Conference Attendees	Grand Ballroom
	SUNDAY SEPTEMBER 22	6:45 AM - 7:45 AM	NFCN Clinic Coordinator Breakfast (By Invitation Only)
6:45 AM - 7:45 AM		Mentoring Breakfast (RSVP Required)	Seacliff AB
7:00 AM - 5:00 PM		Registration	Grand Ballroom Foyer
8:00 AM - 9:00 AM		KEYNOTE 2: The Precision Health Future: Predicting, Preventing and Curing Cancer	Grand Ballroom
9:00 AM - 12:00 PM		SESSION 3: Cancer	Grand Ballroom
10:45 AM - 12:00 PM		SESSION 3B (Concurrent): Mechanisms of NF2 Loss-Driven Tumorigenesis	Seacliff AB
12:00 PM - 12:45 PM		Lunch	Atrium
12:45 PM - 1:45 PM		KEYNOTE 3: Whole Body Imaging of Children with Cancer	Grand Ballroom
1:45 PM - 3:15 PM		SESSION 4: Diagnostics and Imaging	Grand Ballroom
3:10 PM - 3:40 PM		Break	Grand Ballroom Foyer
3:40 PM - 4:40 PM		SESSION 4: Diagnostics and Imaging (Part 2)	Grand Ballroom
4:45 PM - 5:05 PM		Poster Advertisements - Basic Science & Clinical Science	Grand Ballroom
5:05 PM - 7:05 PM		Poster Session - Basic Science & Clinical Science	Pacific H-O
7:00 PM - 10:00 PM		REINS Meeting	Marina Room
MONDAY SEPTEMBER 23		6:45 AM - 7:45 AM	Breakfast
	7:00 AM - 7:55 AM	Funding Opportunities Breakfast (RSVP Required)	Seacliff A
	8:00 AM - 9:00 AM	KEYNOTE 4: Recent Advances in Neurobiology and Management of Neuropathic Pain	Grand Ballroom
	9:00 AM - 11:00 AM	SESSION 5: Pain and Itch	Grand Ballroom
	11:00 AM - 12:00 PM	SESSION 6: Metabolic Rewiring in NF2 Mutant Tumors	Grand Ballroom
	12:00 PM - 1:00 PM	Lunch on Your Own	
	12:00 PM - 1:00 PM	Clinical Care Advisory Board Lunch (By Invitation Only)	Seacliff C
	1:00 PM - 3:00 PM	SESSION 7A (Concurrent): Cutaneous Neurofibromas – Bench to Bedside	Seacliff AB
	2:00 PM - 3:00 PM	SESSION 7B (Concurrent): Genetics of NF2 and Schwannomatosis	Seacliff AB
	3:00 PM - 3:30 PM	Break	Grand Ballroom Foyer
	3:30 PM - 5:00 PM	SESSION 8: Targeted Gene Editing and Gene Therapy for Neurofibromatosis	Grand Ballroom
TUESDAY SEPTEMBER 24	5:15 PM - 7:15 PM	SESSION 9A (Concurrent): Basic Science Platform Presentations	Seacliff AB
	5:15 PM - 7:15 PM	SESSION 9B (Concurrent): Clinical Science Platform Presentations	Grand Ballroom
	7:00 AM - 8:00 AM	Breakfast on Your Own	
	8:15 AM - 9:00 AM	KEYNOTE 5: Perspectives of a "Long-Term" Recklinologist Focusing on the Future	Grand Ballroom
	9:00 AM - 10:00 AM	Oral Poster Presentations & Awards	Grand Ballroom
	10:00 AM - 11:30 AM	SESSION 10: Animal Models	Grand Ballroom
	11:30 AM - 11:45 AM	Break	Grand Ballroom Foyer
	11:45 AM - 12:45 PM	SESSION 11: Second NF Hackathon Outcome	Grand Ballroom
	12:45 PM - 1:05 PM	SESSION 12: Consortia Update	Grand Ballroom
	1:05 PM - 1:20 PM	CONFERENCE WRAP-UP	Grand Ballroom
1:30 PM - 4:00 PM	OPG Consortium (By Invitation)	Seacliff B	



Allan Belzberg, MD, *Professor of Neurosurgery, Johns Hopkins School of Medicine / Hospital*

Dr. Belzberg is the George J Heuer Professor of Neurosurgery at The Johns Hopkins School of Medicine / Hospital. He is the Director of Peripheral Nerve Surgery, and provides care to patients with a variety of nerve pathology. Within the multi-disciplinary comprehensive Neurofibromatosis Clinic, he treats patients suffering from a variety of benign and malignant tumors. His expertise in both spinal and peripheral nerve surgery allow him to remove the most challenging nerve tumors and reconstruct both the spine and peripheral nerves. Dr. Belzberg is a clinician scientist interested in neuropathic pain and is the co-director of the Neurosurgery Pain Research Institute with 75 million dollars of philanthropic funding. Dr. Belzberg has an extensive publication record concerning the pathophysiology of painful nerves. His laboratory described a novel animal model of neuropathic pain that allows the investigator to study both stimulus evoked mechanical hyperalgesia and phenotype change of axons exposed to degenerating axons. He is the PI of the International Schwannomatosis Database currently supported by the Children's Tumor Foundation. Dr. Belzberg is involved in basic science research concerning gene regulation in Schwannomatosis and is also a federal funded investigator developing a biomarker for malignant nerve tumor. Dr. Belzberg is co-director of the multi-disciplinary Nerve Injury Program at the Kennedy Krieger Institute, is a past President of the American Society for Peripheral Nerve and has served as a scientific advisor to a broad spectrum of health care entities including Neurofibromatosis Inc., Axogen, Spinal Kinetics and Medtronic. Dr. Belzberg, born in Montreal Canada, is a graduate of the University of British Columbia, University of Calgary and McGill University. He was awarded a prestigious McLaughlin Foundation Fellowship and travelled to Johns Hopkins where he has remained.



Juha Peltonen, MD, *Professor, Institute of Biomedicine, University of Turku, Finland*

Juha Peltonen received degrees of MD (1981) and PhD (1985) "Connective tissue in von Recklinghausen's neurofibromatosis" at the University of Turku, Finland. In 1987, he moved to the US to serve as postdoc and later as associate professor, Jefferson Institute of Molecular Medicine, Thomas Jefferson University, Philadelphia, PA. On returning to Finland in 1990, Dr. Peltonen has worked as professor at the Universities of Oulu and Turku. The cellular composition and development of dermal neurofibromas, and skeletal manifestations in NF1 have been the main interests of Dr. Peltonen. More recent approaches include total population analyses of cancer in NF1. Dr. Peltonen's group has established the Finnish Neurofibromatosis Registry which is the first total population based and comprehensive neurofibromatosis registry (JID 135:904-906, 2015). The Finnish NF Registry has enabled analyses on e.g. the distinctive cancer associations in patients with NF1 (JCO 34:1978-1986, 2016), and elucidation of the natural history of NF1.

<http://orcid.org/0000-0002-5732-4167>
<http://www.researcherid.com/rid/C-2817-2008>
https://www.researchgate.net/profile/Juha_Peltonen2/



Jill Weimer, PhD, *Associate Scientist and Senior Director of Therapeutic Development, Sanford Research*

Dr. Jill Weimer is a developmental neuroscientist and oversees the management and continued development of the translational arm of Sanford Research in Sioux Falls, South Dakota. She started at Sanford Research in 2009 as an assistant scientist, and her research program focuses on the molecular mechanisms mediating development of the cerebral cortex and how disruption in these processes can lead to a whole host of neural pediatric disorders, including Batten's disease and Neurofibromatosis Type 1. Dr. Weimer grew up in north central Missouri and moved to upstate New York where she received her bachelor's degree and Ph.D. in neuroscience from the University of Rochester. She completed her postdoctoral training in the Neuroscience Research Center at the University of North Carolina in Chapel Hill with a focus on developmental neuroscience.

2019 NF Conference Keynote Speakers



Allan Basbaum, PhD, FRS, *Professor and Chair, Department of Anatomy, University of California, San Francisco*

Born in Montreal, Quebec, Allan Basbaum received his BSc from McGill University and his PhD from the University of Pennsylvania. After postdoctoral research at the University College London and then at the University California San Francisco he was appointed to the faculty of UCSF, where he is presently professor and Chair of the Department of Anatomy. His research addresses the molecular mechanisms that underlie the generation of persistent pain after tissue or nerve injury. Most recently, his laboratory has focused on novel approaches to overcoming the neurological consequences of peripheral nerve damage, by transplanting embryonic cortical inhibitory precursor cells into the spinal cord. He has served as Editor-in-Chief of PAIN, the journal of the International Association for the Study of Pain. He served as Co-Chair of the Steering Committee of the

Intergovernmental Pain Research Coordinating Committee and was recently appointed to the NINDS Council. He is a member of the American Academy of Arts and Sciences, the National Academy of Medicine, the National Academy of Science and is a fellow of the Royal Society in the United Kingdom.



Heike Elisabeth Daldrup-Link, MD, PhD, *Department of Radiology, Stanford University*

Dr. Heike Elisabeth Daldrup-Link, MD, PhD, is a Professor of Radiology, Director of the Pediatric Molecular Imaging Program, Co-Director of the Cancer Imaging Program and Associate Chair for Diversity in the Department of Radiology at Stanford University. Dr. Daldrup-Link is a physician-scientist with sub-specialization in pediatric oncology imaging. Dr. Daldrup-Link has both uncovered basic science principles for pediatric cancer imaging in an NIH funded-basic science lab and brought the most promising imaging innovations to her patients' bedside. Dr. Daldrup-Link has published more than 160 scientific publications with 8815 citations in scientific journals. Dr. Daldrup-Link's recognitions include the Roentgen Award, the AUR New Investigators Award, the Caffey Award (twice), the UCSF Innovations in Science Award, the Berdon Award (twice), the

Distinguished Investigator Award of the Academy of Radiology Research, Membership in the American Society for Clinical Investigation (ASCI) and Fellow of the American Institute for Medical and Biomedical Engineering (AIMBE), among others.



Stephen C. Groft, PharmD, *Senior Advisor to the Director, National Center for Advancing Translational Sciences, NIH*

Steve is a Senior Advisor to the Director, National Center for Advancing Translational Sciences (NCATS) at NIH. Previously, he assisted in establishing the Office of Orphan Products Development at FDA in 1982. In 1989 he established a rare diseases initiative at NIH leading to a role as the Director of the Office of Rare Diseases Research (ORDR) at the NIH from 1993-2014. Activities included the development of the Genetic and Rare Diseases Information Center (GARD), the International Rare Diseases Research Consortium (IRDIRC), the International Conference on Rare Diseases and Orphan Drugs (ICORD), the Rare Diseases Clinical Research Network (RDCRN), assisting in the development of the Undiagnosed Diseases Program at NIH's Clinical Center Hospital, and developing common data elements for patient registries and

expanding the International Classification of Diseases XI to include more rare diseases.

His major focus has been on stimulating research with rare diseases and orphan products and developing information for patients, families, health care providers, research investigators, the biopharmaceutical industry, and the public. The emphasis included information about rare diseases, active and completed clinical trials, ongoing research, and patient advocacy groups. He has authored 85 journal articles, book chapters and the co-editor of 2 books on Rare Diseases Epidemiology. He has also made more than 310 presentations on rare diseases.

2019 NF Conference Keynote Speakers



Lloyd B. Minor, MD, *Dean of the Stanford University School of Medicine*

Lloyd B. Minor, MD, is a scientist, surgeon, and academic leader. He is the Carl and Elizabeth Naumann Dean of the Stanford University School of Medicine, a position he has held since December 2012. He is also a professor of Otolaryngology–Head and Neck Surgery and a professor of Bioengineering and of Neurobiology, by courtesy, at Stanford University.

As dean, Dr. Minor plays an integral role in setting strategy for the clinical enterprise of Stanford Medicine, an academic medical center that includes the Stanford University School of Medicine, Stanford Health Care, and Stanford Children’s Health and Lucile Packard Children’s Hospital Stanford. With his leadership, Stanford Medicine has established a strategic vision to lead the biomedical revolution in Precision Health, a fundamental shift to more proactive and personalized health care that empowers people to lead healthy lives.

Before coming to Stanford, Dr. Minor was provost and senior vice president for academic affairs of The Johns Hopkins University. Prior to his appointment as provost in 2009, Dr. Minor served as the Andelot Professor and director (chair) of the Department of Otolaryngology–Head and Neck Surgery in the Johns Hopkins University School of Medicine and otolaryngologist-in-chief of The Johns Hopkins Hospital.

With more than 140 published articles and chapters, Dr. Minor is an expert in balance and inner ear disorders. In the medical community, Dr. Minor is perhaps best known for his discovery of superior canal dehiscence syndrome, a debilitating disorder characterized by sound- or pressure-induced dizziness. He subsequently developed a surgical procedure that corrects the problem and alleviates symptoms.

In 2012, Dr. Minor was elected to the National Academy of Medicine.



Vincent M. Riccardi, MD, MBA, *Retired, The Neurofibromatosis Institute*

Vincent M. Riccardi, MD, MBA, obtained his undergraduate degree at UCLA (1962), his medical school degree at Georgetown University (1966) and his Internal Medicine training at the University of Pittsburgh (1968). His three-year Genetics Fellowship at the Massachusetts General Hospital was completed in 1972, with an interruption for a U.S. Army stint at the rank of Major in the Medical Corps. In 1973-1975 he was an Assistant Professor in Genetics at the University of Colorado in Denver and an Associate Professor at the Medical College of Wisconsin in Milwaukee from 1975-1977. In all of these positions he had a special interest in Neurofibromatosis, accruing a substantial clinical experience in this regard. He confirmed his commitment to NF by establishing and directing the Baylor NF Program (BNFP) in Houston, TX, at Baylor College of Medicine and the M.D. Anderson Hospital (1977-1990). In 1990 he moved to Los Angeles, where he became a Clinical Professor of Genetics at UCLA and established The Neurofibromatosis Institute (TNFI). In 1993, he graduated Magna Cum Laude with an MBA from the University of La Verne. In the 47 years since 1972, he has formally engaged over 1,000 persons with NF1 and a similar number less formally. In addition, his laboratory cell culture and biochemistry experience during this time period has contributed substantially to understanding NF1. He has also accumulated an Archive of Biomedical Publications, primarily focusing on NF, in EndNote and an Annotated Bibliography comprising more than 18,000 publications. He continues his professional commitment to NF1 as Director of TNFI and multiple extramural commitments, including the Department of Defense NFRP, CTF and NTAP (External Advisory Committee and Mentor to the Francis S. Collins Scholars).

As regards the CTF meeting presentation on September 24, 2019, he has NO conflicts of interest.

AGENDA

Friday · September 20, 2019

5:00 PM	8:00 PM	REGISTRATION	Grand Ballroom Foyer
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5:00 PM	10:00 PM	POSTER SETUP	Pacific H-0
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Saturday · September 21, 2019

7:00 AM	5:00 PM	REGISTRATION	Grand Ballroom Foyer
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7:30 AM	12:00 PM	CLINICAL CARE SYMPOSIUM	Grand Ballroom
		Session Co-Chairs: Scott Plotkin, MD, PhD, <i>Massachusetts General Hospital</i> ; Elizabeth Schorry, MD, <i>Cincinnati Children's Hospital</i> ; Pamela Trapane, MD, <i>University of Florida Health Jacksonville</i> ; Nicole Ullrich, MD, PhD, <i>Boston Children's Hospital</i>	
7:30 AM		Breakfast Available for Symposium Attendees	Grand Ballroom Foyer
8:00 AM	8:05 AM	Welcome and Introduction Scott Plotkin, MD, PhD, <i>Massachusetts General Hospital</i>	
8:05 AM	8:30 AM	Revised Diagnostic Criteria for NF1, NF2, and Schwannomatosis NF1 Eric Legius, MD, PhD, <i>University of Leuven, Belgium</i>	
8:30 AM	9:00 AM	NF2 and Schwannomatosis Scott Plotkin, MD, PhD, <i>Massachusetts General Hospital</i>	
9:00 AM	9:30 AM	Health Supervision for Children with NF1: ACMG/AAP Guidelines David T. Miller, MD, PhD and Nicole Ullrich, MD, PhD, <i>Boston Children's Hospital</i>	
9:30 AM	9:40 AM	Strategic Vision for the Neurofibromatosis Clinic Network Heather Radtke, MS, CGC, <i>Children's Tumor Foundation</i>	
9:40 AM	9:55 AM	BREAK	Grand Ballroom Foyer
9:55 AM	10:30 AM	Quality Metrics Project Description and Discussion Justin Jordan, MD, MPH, <i>Harvard Medical School</i>	
10:30 AM	10:55 AM	Clinical Patient Management System of the European Reference Network (ERN) Gareth Evans, MD, <i>University of Manchester, UK</i>	
		Diagnostic Dilemmas and Case Studies Facilitator: Peter de Blank, MD, MSCE, <i>Cincinnati Children's Hospital</i> Panel: Matthias Karajannis, MD, MS, <i>Memorial Sloan Kettering Cancer Center</i> ; Scott Plotkin, MD, PhD, <i>Massachusetts General Hospital</i> ; Tena Rosser, MD, <i>Children's Hospital Los Angeles</i> ; Elizabeth Schorry, MD, <i>Cincinnati Children's Hospital</i> ; Pamela Trapane, MD, <i>University of Florida Health, Jacksonville</i> ; Pierre Wolkenstein, MD, PhD, <i>Henri-Mondor Hospital, Paris East University, France</i>	
11:55 AM	12:00 PM	Conclusion Scott Plotkin, MD, PhD, <i>Massachusetts General Hospital</i>	

12:45 PM	1:00 PM	CONFERENCE KICK-OFF	Grand Ballroom
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1:00 PM	2:00 PM	KEYNOTE SPEECH 1: From Patients to Patients – And a Whole Lot In-Between Stephen Groft, PharmD, <i>Senior Advisor to the Director, National Center for Advancing Translational Science (NCATS) at NIH</i>	Grand Ballroom
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2:00 PM	4:00 PM	SESSION 1: NATURAL HISTORY OF NEUROFIBROMATOSIS	Grand Ballroom
		Session Co-Chairs: Brigitte Widemann, MD, <i>National Cancer Institute</i> ; Ana-Maria Vranceanu, PhD, <i>Harvard University</i> ; Ethan Lester, PhD, <i>Harvard University</i>	
2:00 PM	2:10 PM	Introduction Brigitte Widemann, MD, <i>National Cancer Institute</i>	

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Saturday · September 21, 2019

2:10 PM	2:35 PM	Natural History of the NF1 Cognitive Phenotype Belinda Barton, PhD, <i>Children's Hospital of Westmead, University of Sydney, Australia</i>	
2:35 PM	2:50 PM	Platform: Physical Functioning Outcomes in Children with Neurofibromatosis Type 1 (NF1) and Plexiform Neurofibroma (PN) Motor Morbidity on SPRINT: a Phase II Trial of the MEK 1/2 Inhibitor Selumetinib (AZD6244, ARRY-142886; NCT01362803) Pam Wolters, PhD, <i>National Cancer Institute</i>	
2:50 PM	3:05 PM	Platform: Long-term Follow-up of Adult Neurofibromatosis Type 1 Patients Using Whole-body MRI Demonstrates Dynamic Changes in Internal Neurofibroma Size Ina Ly, MD, <i>Massachusetts General Hospital</i>	
3:05 PM	3:20 PM	Platform: Autism Spectrum Disorder and Social Functioning in Children with Neurofibromatosis Type 1: Preliminary Findings from the PANDA Study Jonathan Payne, PsyD, <i>Murdoch Children's Research Institute</i>	
3:20 PM	3:35 PM	Platform: Longitudinal Examination of Attention Problems and Anxiety in Children with Neurofibromatosis Type 1 Kristin Lee, MS, <i>University of Wisconsin-Milwaukee</i>	
3:35 PM	3:50 PM	Platform: Modeling of Long-term NF1 Natural History Data to Predict Plexiform Neurofibroma Growth Cody Peer, PhD, <i>National Cancer Institute</i>	
4:00 PM	4:30 PM	BREAK	Grand Ballroom Foyer
4:30 PM	5:35 PM	SESSION 2: PSYCHOSOCIAL ISSUES OF THE NF PATIENT Session Co-Chairs: Ana-Maria Vranceanu, PhD, Harvard University; Ethan Lester, PhD, Harvard University	Grand Ballroom
4:35 PM	4:55 PM	Virtual Mind-Body Groups Improve Resiliency Factors in Internationally Diverse Patients with NF1, NF2 and Schwannomatosis: Results of Three Randomized Controlled Trials (RCTs) in Adults, Adolescents and Patients Who Are Deaf Ethan Lester, PhD, <i>Harvard University</i>	
4:55 PM	5:10 PM	Platform: Acceptance and Commitment Training (ACT) in Individuals with NF1 and Plexiform Neurofibroma Tumors (PNs) and Chronic Pain: How Important is Treatment Engagement in Daily Life? Staci Martin, PhD, <i>Pediatric Oncology Branch, National Cancer Institute, NIH</i>	
5:10 PM	5:25 PM	Platform: Externalizing Symptoms Drive Social Functioning Difficulties in Children with Neurofibromatosis Type 1 (NF1) Allison del Castillo, <i>Children's National Health System</i>	
5:30 PM	6:30 PM	MENTORING SESSION: "SPEED-DATING WITH THE EXPERTS"	Seacliff AB
6:30 PM	7:30 PM	RECEPTION AND SPECIAL POSTER SESSION FOR NF FORUM ATTENDEES - All Welcome	Pacific H-O
7:45 PM	9:45 PM	Welcome Dinner for NF Forum and NF Conference Attendees	Grand Ballroom

Sunday · September 22, 2019

6:45 AM	7:45 AM	NFCN Clinic Coordinator Breakfast (By Invitation Only)	Seacliff C
6:45 AM	7:45 AM	Mentoring Breakfast (RSVP Required)	Seacliff AB
6:45 AM	7:45 AM	Breakfast on Your Own	
7:00 AM	5:00 PM	Registration	Grand Ballroom Foyer
8:00 AM	9:00 AM	KEYNOTE SPEECH 2: The Precision Health Future: Predicting, Preventing and Curing Cancer Lloyd B. Minor, MD, <i>Carl and Elizabeth Naumann Professor, Dean of Stanford University School of Medicine</i>	Grand Ballroom

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Sunday · September 22, 2019

9:00 AM	12:00 PM	SESSION 3: CANCER	Grand Ballroom
		Session Co-Chairs: Rebecca Dodd, PhD, <i>University of Iowa</i> ; Michael Fisher, MD, <i>Children's Hospital of Philadelphia</i> ; Juha Peltonen, MD, PhD, <i>University of Turku, Finland</i>	
9:00 AM	9:25 AM	MPNST: From Beginning to End Luis Parada, PhD, <i>Memorial Sloan Kettering Cancer Institute</i>	
9:25 AM	9:40 AM	Platform: Somatic CRISPR/Cas9 Tumorigenesis Approaches to Study Myeloid Cell Function in MPNST Rebecca Dodd, PhD, <i>University of Iowa</i>	
9:40 AM	9:55 AM	Platform: Pharmacogenomic and Synthetic Lethal Genetic Screens Reveal Hidden Vulnerabilities and New Therapeutic Approaches for Treatment of NF1-Associated Tumors and Malignancies Kyle Williams, PhD, <i>University of Minnesota</i>	
9:55 AM	10:10 AM	Platform: Defining the Mechanisms Underlying Pediatric Brain Tumor Penetrance Nicole Brossier, MD, PhD, <i>Washington University - St. Louis</i>	
10:10 AM	10:15 AM	"Short Burning Questions"	
10:15 AM	10:45 AM	BREAK	Grand Ballroom Foyer
10:45 AM	11:10 AM	Preclinical and Clinical Studies in NF1-Associated Blood Cancers Kevin Shannon, PhD, <i>University of California San Francisco</i>	
11:10 AM	11:35 AM	Development and Progression of NF1-Associated Peripheral Nerve Sheath Tumors Eduard Serra, PhD, <i>The Institute for Health Science Research Germans Trias i Pujol (IGTP)</i>	
11:35 AM	11:50 AM	Platform: Phase II Trial of the MEK 1/2 Inhibitor Selumetinib (AZD6244, ARRY-142886 Hydrogen Sulfate) in Adults with Neurofibromatosis Type 1 (NF1) and Inoperable Plexiform Neurofibromas (PN) Geraldine O'Sullivan Coyne, MD, <i>National Cancer Institute</i>	
11:50 AM	12:00 PM	Wrap Up and Q&A to All Speakers	
10:45 AM	12:00 PM	SESSION 3B (CONCURRENT): MECHANISMS OF NF2 LOSS-DRIVEN TUMORIGENESIS	Seacliff AB
		Session Chair: Chunling Yi, PhD, <i>Georgetown University</i>	
10:45 AM	11:05 AM	Mechanistic Underpinnings of TORC1 Activation in NF2 Mutant Tumors Filippo Giancotti, MD, PhD, <i>Anderson Cancer Center</i>	
11:05 AM	11:25 AM	The Hippo-YAP Pathway in Schwannoma – Novel Functions and Therapeutic Implications Joseph Kissil, PhD, <i>The Scripps Institute</i>	
11:25 AM	11:45 AM	NF2 and Cell Contact Regulation of TEAD Stability and Function Barry Gumbiner, PhD, <i>University of Washington/Seattle Children's Hospital</i>	
11:45 AM	12:00 PM	Lipid Signaling in Hippo Pathway Regulation and Cancer Wenqi Wang, PhD, <i>UC Irvine</i>	
12:00 PM	12:40 PM	Lunch	Atrium
12:45 PM	1:45 PM	KEYNOTE SPEECH 3: Whole Body Imaging of Children with Cancer Heike Daldrup-Link, MD, PhD, <i>Department of Radiology, Stanford University</i>	Grand Ballroom
1:45 PM	3:15 PM	SESSION 4: DIAGNOSTICS AND IMAGING	Grand Ballroom
		Session Co-Chairs: Shivani Ahlawat, MD, <i>Johns Hopkins University</i> ; Rosalie Ferner, MD, <i>Guy's and St. Thomas' NHS Trust</i> ; Michel Kalamarides, MD, PhD, <i>Hôpital Pitié-Salpêtrière, Paris</i>	
1:45 PM	2:10 PM	Quantitative Imaging Analysis in Assessment and Prediction of Tumor Response Wenli Cai, PhD, <i>Massachusetts General Hospital/Harvard University</i>	
2:10 PM	2:25 PM	Platform: Feasibility of Magnetic Resonance-Guided High Intensity Focused Ultrasound for Treatment of Atypical Neurofibromas/Distinct Nodular Lesions Caitlin Tydings, <i>Children's National Medical Center</i>	

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2:25 PM	2:40 PM	Platform: Screening Whole Body MRI Using Diffusion Weighted Imaging in Neurofibromatosis Type 1 – Is Intravenous Contrast Medium Necessary? Shivani Ahlawat, MD, <i>The Johns Hopkins University School of Medicine</i>	
2:40 PM	3:10 PM	Cases with Audience Participation: NF1, NF2 and SWN Discussion Lead by Chairs	
3:10 PM	3:40 PM	BREAK	Grand Ballroom Foyer
3:40 PM	4:40 PM	SESSION 4: DIAGNOSTICS AND IMAGING (PART 2)	Grand Ballroom
3:40 PM	4:00 PM	Cranial Nerves Tractography: A Review Michel Kalamarides, MD, PhD, <i>Hôpital Pitié-Salpêtrière Paris</i>	
4:00 PM	4:15 PM	Platform: Non-Ossifying Fibromas in Patients Enrolled in the NCI NF1 Natural History Study Eva Dombi, MD, <i>National Institutes of Health</i>	
4:45 PM	5:05 PM	POSTER ADVERTISEMENTS	Grand Ballroom
4:45 PM	4:55 PM	Basic Science	
4:55 PM	5:05 PM	Clinical Science	
5:05 PM	7:05 PM	POSTER SESSION Combined Basic and Clinical Science Poster Session. Refreshments to be provided.	Pacific H-O
7:00 PM	10:00 PM	REiNS Meeting	Marina Room

Monday · September 23, 2019

6:45 AM	7:45 AM	Breakfast	Atrium
7:00 AM	7:55 AM	Funding Opportunities (RSVP Required)	Seacliff A
8:00 AM	9:00 AM	KEYNOTE SPEECH 4: Recent Advances in Neurobiology and Management of Neuropathic Pain Allan Basbaum PhD, FRS, <i>Professor and Chair, Department of Anatomy, University of California, San Francisco</i>	Grand Ballroom
9:00 AM	11:00 AM	SESSION 5: PAIN AND ITCH Session Co-Chairs: Michael Caterina, MD, PhD, <i>Johns Hopkins School of Medicine</i> ; Vanessa Merker, PhD, <i>ENRM Veterans Hospital, Boston</i> ; Shawn Kwatra, MD, <i>Johns Hopkins University School of Medicine</i>	Grand Ballroom
9:00 AM	9:30 AM	The Role of Mrgprs in Itch Sensation Xinzhong Dong, PhD, <i>Johns Hopkins School of Medicine</i>	
9:30 AM	10:00 AM	Complementary and Integrative Health Therapies for Pain Stephanie Taylor, MD, <i>VA Greater Los Angeles Healthcare System</i>	
10:00 AM	10:20 AM	BREAK	Grand Ballroom Foyer
10:20 AM	10:40 AM	Platform: Sex-Dependent Differences in Pain and Sleep in a Porcine Model of Neurofibromatosis Type 1 Rajesh Khanna, PhD, <i>University of Arizona</i>	
10:40 AM	11:00 AM	Platform: Schwann Cells with LZTR1 and SMARCB1 Mutations Have Different Secretomes That Influence Pain Fatima Banine, PhD, <i>Oregon Health & Science University</i>	
11:00 AM	12:00 PM	SESSION 6: METABOLIC REWIRING IN NF2 MUTANT TUMORS Session Chair: Filippo Giancotti, MD, PhD, <i>MD Anderson Cancer Center</i>	Grand Ballroom
11:00 AM	11:20 AM	The Hippo Pathway in Cell Growth and Cancer Kunlian Guan, PhD, <i>UC San Diego</i>	

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Monday · September 23, 2019

11:20 AM	11:40 AM	Ferroptosis, Mechanisms and Role in Disease Xuejun Jiang, PhD, <i>Memorial Sloan Kettering Cancer Center</i>	
11:40 AM	12:00 PM	Harnessing Yap/Taz Signaling Network for Treatment of NF2 Tumors Chunling Yi, PhD, <i>Georgetown University</i>	
12:00 PM	1:00 PM	Lunch on Your Own	
12:00 PM	1:00 PM	Clinical Care Advisory Board Lunch (By Invitation Only)	Seacliff C
1:00 PM	3:00 PM	SESSION 7A (CONCURRENT): CUTANEOUS NEUROFIBROMAS – BENCH TO BEDSIDE	Seacliff AB
		Session Co-Chairs: Jaishri Blakeley, MD, <i>Johns Hopkins University Hospital</i> ; Matthew Steensma, MD, <i>Van Andel Research Institute</i> ; Eduard Serra, PhD, <i>The Institute for Health Science Research German Trias i Pujol</i>	
1:00 PM	1:25 PM	The Biology of Cutaneous Neurofibroma: Current Understanding and Future Perspectives Lu Le, MD, PhD, <i>University of Texas Southwestern</i>	
1:25 PM	1:50 PM	Cutaneous Neurofibromas: Present, Future Pierre Wolkenstein, MD, PhD, <i>Hopital Henri-Mondor, Creteil, France</i>	
1:50 PM	2:05 PM	Platform: NF1 Patient Missense Variants Predict a Role for ATM in Modifying Neurofibroma Initiation Yanan Yu, <i>Cincinnati Children's Hospital and University of Cincinnati</i>	
2:05 PM	2:20 PM	Platform: The Role of MicroRNA-155 in Nf1 Neurofibroma Initiation Jiangiang Wu, PhD, <i>Cincinnati Children's Hospital</i>	
2:20 PM	2:35 PM	Platform: Systematic Longitudinal Evaluation of Phenotype Development in a Swine Model of Neurofibromatosis 1 Katherine White, <i>Sanford Research</i>	
2:35 PM	2:50 PM	Platform: Investigating the Role of NF1^{+/-} Fibroblasts in Neurofibromatosis Type I-Associated Cutaneous Neurofibromas Sara Osum, <i>University of Minnesota</i>	
2:50 PM	3:00 PM	Discussion	
2:00 PM	3:00 PM	SESSION 7B (CONCURRENT): GENETICS OF NF2 AND SCHWANNOMATOSIS	Seacliff AB
		Session Chair: Gareth Evans, MD, <i>St. Mary's Hospital, University of Manchester, UK</i>	
2:00 PM	2:20 PM	Implications of Mosaicism in Neurofibromatosis Type 2 Dorothy Halliday, FRCP, PhD, <i>Oxford University</i>	
2:20 PM	2:35 PM	Platform: Higher Estimates of Mosaicism in De Novo Neurofibromatosis Type 2 Following Increased Use of Next Generation Sequencing Miriam Smith, PhD, <i>University of Manchester</i>	
2:35 PM	2:50 PM	Platform: A Phase 0 Pharmacodynamic and Pharmacokinetic Study of Everolimus in Vestibular Schwannoma (VS) and Meningioma Patients Matthias Karajannis, MD, MS, <i>Memorial Sloan Kettering Cancer Center</i>	
3:00 PM	3:30 PM	BREAK	Grand Ballroom Foyer
3:30 PM	5:00 PM	SESSION 8: TARGETED GENE EDITING AND GENE THERAPY FOR NEUROFIBROMATOSIS	Grand Ballroom
		Session Co-Chairs: Rajesh Khanna, PhD, <i>University of Arizona</i> ; Scott Plotkin, MD, PhD, <i>Massachusetts General Hospital</i> ; Aaron Schindeler, PhD, <i>University of Sydney, Australia</i>	
3:30 PM	3:42 PM	Introduction to Gene Therapy Aaron Schindeler, PhD, <i>University of Sydney, Australia</i>	
3:42 PM	3:54 PM	Gene Replacement Therapy for NF2 Marco Giovannini, MD, PhD, <i>UCLA Medical School</i>	

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3:54 PM 4:06 PM **Genome-Guided Therapeutics for NF1**
Bruce Korf, MD, PhD, *University of Alabama at Birmingham*

4:06 PM 4:18 PM **Dissecting Pain in NF1**
Rajesh Khanna, PhD, *University of Arizona*

4:18 PM 4:30 PM **Proactive Engagement of Stakeholders in Developing Clinical Trials for Gene Therapy in NF Patients**
Scott Plotkin, MD, PhD, *Massachusetts General Hospital*

4:30 PM 5:00 PM **Panel Discussion**

5:15 PM 7:15 PM SESSION 9A (CONCURRENT): BASIC SCIENCE PLATFORM PRESENTATIONS Seacliff AB

Session Co-Chairs: David Gutmann, MD, PhD, *Washington University, St. Louis*; Laura Papi, MD, *University of Florence, Italy*; Dawn Quelle, PhD, *University of Iowa*

5:15 PM 5:30 PM **Neurofibromatosis Type 1: A Sweet Story of Metabolism**
Rebekah Tritz, MS, *Vascular Biology Center, Augusta University*

5:30 PM 5:45 PM **MEK Inhibition Ameliorates Social Behaviour Phenotypes in a Spred1 Knockout Mouse Model for RASopathy Disorders**
Sarah Borrie, PhD, *KU Leuven, Belgium*

5:45 PM 6:00 PM **Macrophage Macropinocytosis: A Potential Target to Attenuate Tumor Vascularization in Neurofibromatosis Type 1**
Pushpankur Ghoshal, PhD, *Augusta University*

6:00 PM 6:15 PM **Neurofibromin Also Has a GAP-Independent Activity, Acting as a Transcriptional Co-Repressor for Estrogen Receptor-Alpha**
Eric C. Chang, PhD, *Baylor College of Medicine*

6:15 PM 6:30 PM **Screening for ASD Therapies Using a *Drosophila* Model of NF1**
Alex Dyson, MSci, *University of Manchester, UK*

6:30 PM 6:45 PM **Modelling the Development of NF1-Associated Malignant Peripheral Nerve Sheath Tumors Using Induced Human Pluripotent Stem Cells and Targeted Temporal Transforming Mutations**
Garrett Draper, PhD Student, *University of Minnesota*

6:45 PM 7:00 PM **Proximity Biotinylation Identifies a Set of Conformation Specific Interactions Between Merlin and Cell Junction Proteins**
Robert Hennigan, PhD, *Cincinnati Children's Hospital*

7:00 PM 7:15 PM **Targeting Protein Translation with Rocaglamide and Didesmethylocaglamide to Treat NF1 and NF2 Tumors**
Long-Sheng Chang, *Nationwide Children's Hospital / The Ohio State University*

5:15 PM 7:15 PM SESSION 9B (CONCURRENT): CLINICAL SCIENCE PLATFORM PRESENTATIONS Grand Ballroom

Session Co-Chairs: Justin Jordan, MD, PhD, *Massachusetts General Hospital*; Kaleb Yohay, MD, *NYU Langone Medical Center*; Sirku Peltonen, MD, *University of Turku, Finland*

5:15 PM 5:30 PM **Prediction of Hearing Prognosis in NF2 Related Vestibular Schwannoma by Genetic Analysis**
Yu Teranishi, MD, *Department of Neurosurgery, Faculty of Medicine, The University of Tokyo, Japan*

5:30 PM 5:45 PM **Early Development in Neurofibromatosis 1 (EDEN): Developmental Trajectory and Behavioural Phenotype of Infants with NF1**
Shruti Garg, PhD, *University of Manchester, UK*

5:45 PM 6:00 PM **A Longitudinal Analysis of Cognitive Predictors of Academic Achievement in Children and Young Adults with Neurofibromatosis Type 1 (NF1)**
Taryn Allen, PhD, *National Cancer Institute*

6:00 PM 6:15 PM **Cognitive Functioning in Adults with NF1: Preliminary Results of a Danish Population-Based Comparison Cohort Study**
Karoline Doser, MA, *Danish Cancer Society*

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Monday · September 23, 2019

6:15 PM	6:30 PM	<p>Symptoms, Location and Management of 77 Children with Neurofibromatosis Type 1 Plexiform Neurofibroma in the National Complex Neurofibromatosis Service, Guy's Hospital, UK 2018-2019 Yoshua Collins-Sawaragi, MD, <i>London Children's Hospital</i></p>
6:30 PM	6:45 PM	<p>Characterizing NF1-Associated Skeletal Manifestations with Single-Cell Resolution and the Effects of MEK Inhibition on Bone Mineral Density in Children with NF1 and Plexiform Neurofibromas Jonathan J Rios, PhD, <i>Texas Scottish Rite Hospital for Children</i></p>
6:45 PM	7:00 PM	<p>Assessment of Pulmonary Function in Patients with Neurofibromatosis Type 1 and Airway Associated Plexiform Neurofibromas Before and After Treatment with Selumetinib Andrea Gross, MD, <i>National Institutes of Health</i></p>
7:00 PM	7:15 PM	<p>Validating Measurement Techniques for Cutaneous Neurofibromas in Clinical Trials Scott Plotkin, MD, PhD, <i>Massachusetts General Hospital</i></p>

Tuesday · September 24, 2019

7:00 AM	8:15 AM	Breakfast on Your Own	
8:15 AM	9:00 AM	<p>KEYNOTE SPEECH 5: Perspectives of a “Long-Term” Recklinologist Focusing on the Future Vincent Riccardi, MD, <i>Retired, The Neurofibromatosis Institute</i></p>	Grand Ballroom
9:00 AM	10:00 AM	ORAL POSTER PRESENTATIONS & AWARDS	Grand Ballroom
10:00 AM	11:30 AM	<p>SESSION 10: ANIMAL MODELS</p> <p>Session Co-Chairs: Marco Giovannini, MD, PhD, <i>UCLA School of Medicine</i>; Nancy Ratner, PhD, <i>Cincinnati Children's Hospital Medical Center</i></p>	Grand Ballroom
10:00 AM	10:20 AM	<p>Modeling NF1 in Drosophila James Walker, PhD, <i>Harvard University</i></p>	
10:20 AM	10:35 AM	<p>Platform: Inhibition of the Hippo Pathway in Schwann Cell Lineage Lead to Schwannoma Development Zhiguo Chen, PhD, <i>UT Southwestern Medical Center</i></p>	
10:35 AM	10:55 AM	<p>Mouse Models of Neurofibromatosis Type 1 (NF1)-Associated Low- and High-Grade Glioma Yuan Zhu, PhD, <i>Children's National Medical Center</i></p>	
10:55 AM	11:15 AM	<p>Development and Validation of a Novel NF2 GEMM to Facilitate Preclinical Studies Joseph Kissil, PhD, <i>The Scripps Research Institute</i></p>	
11:15 AM	11:30 AM	<p>Platform: The Role of Neurofibromin in Neurocognitive Impairment, CNS Cell Function, and Differentiation in a Porcine Model of Neurofibromatosis Type 1 Vicki Swier Mosher, PhD, <i>Sanford Research</i></p>	
11:30 AM	11:45 AM	BREAK	Grand Ballroom Foyer
11:45 AM	12:45 PM	<p>SESSION 11: SECOND NF HACKATHON OUTCOME</p> <p>Salvatore La Rosa, PhD, <i>Children's Tumor Foundation Chief Scientific Officer</i> The winning teams will be presenting their findings during this session.</p>	Grand Ballroom
12:45 PM	1:05 PM	<p>SESSION 12: CONSORTIA UPDATE</p> <p>Michael Fisher, MD, <i>Children's Hospital of Philadelphia, Chair, CDMRP NF Consortium</i></p>	Grand Ballroom
1:05 PM	1:20 PM	CONFERENCE WRAP-UP	Grand Ballroom
1:30 PM	4:00 PM	OPG Consortium (By Invitation)	Seacliff B

PARTICIPANTS

Attendees List – 2019 NF Conference

LAST NAME	FIRST NAME	SUFFIX	COMPANY	WORK COUNTRY	WORK STATE
Abaricia	Sarah	R.N., M.S.	Washington University	USA	Missouri
Aguilar-Bonilla	Ana	M.D.	Orlando Health Arnold Palmer Hospital	USA	Florida
Ahlawat	Shivani	M.D.	Johns Hopkins University	USA	Maryland
Akshintala	Vandana	M.D.	National Cancer Institute	USA	Maryland
Allaway	Robert	Ph.D.	Sage Bionetworks	USA	Washington
Allen	Taryn	Ph.D.	Leidos Biomedical Research	USA	Maryland
Amin	Suvina		AstraZeneca Pharmaceuticals	USA	Maryland
Anastasaki	Corina	Ph.D.	Washington University School of Medicine	USA	Missouri
Angulo	Ivan	Ph.D.	Healx	United Kingdom	Cambridgeshire
Anstett	Kara	M.S., CGC	NYU Langone Health	USA	New York
Ayter	Sükriye	Ph.D.	TOBB ETU University	Turkey	
Baker	Laura	M.S., CGC	Nemours Center for Cancer and Blood Disorders	USA	Delaware
Bakker	Annette	Ph.D.	Children's Tumor Foundation	USA	New York
Baldwin	Andrea	R.N., CPNP	Leidos Biomedical Research	USA	Maryland
Banerjee	Jineta	Ph.D.	Sage Bionetworks	USA	Washington
Banine	Fatima	Ph.D.	Oregon Health & Science University	USA	Oregon
Barton	Belinda	Ph.D.	The Children's Hospital at Westmead	Australia	New South Wales
Basbaum	Allan	Ph.D.	University of California San Francisco	USA	California
Beach	Paul			USA	Illinois
Beauchamp	Roberta		Massachusetts General Hospital	USA	Massachusetts
Bedwell	David	Ph.D.	University of Alabama at Birmingham	USA	Alabama
Beizberg	Allan	M.D.	Johns Hopkins Hospital	USA	Maryland
Berger	Carly	Student	Children's National Medical Center	USA	District of Columbia
Bielamowicz	Kevin	M.D.	Arkansas Children's Hospital	USA	Arkansas
Bird-Lieberman	Georgina		Childhood Tumor Trust	United Kingdom	
Blanco	Ignacio	M.D., Ph.D.	HUGTIP	Spain	Barcelona
Bokstein	Felix	M.D.	Tel Aviv Sourasky Medical Center, Gilbert Israeli Neurofibromatosis Center	Israel	
Bollag	Gideon	Ph.D.	Research	USA	California
Bora	Naba	Ph.D.	Dept Of Defense, CDMRP	USA	Maryland
Bornhorst	Miriam	M.D.	Children's National Medical Center	USA	District of Columbia
Borrie	Sarah	Ph.D.	KU Leuven, Leuven, BE	Belgium	Vlaams Brabant
Bouley	Stephanie	Ph.D.	Massachusetts General Hospital	USA	Massachusetts
Boyer	John	Ph.D.	AstraZeneca	United Kingdom	Cambridgeshire
Bracegirdle	Sarah		Ashfield Healthcare Communications	United Kingdom	Cheshire
Brainin	Rob		BOD Children's Tumor Foundation	USA	Massachusetts
Brault	Jennifer	M.D.	Vanderbilt University Medical Center	USA	Tennessee
Brems	Hilde	Ph.D.	Center for Human Genetics/ UZ-KU Leuven	Belgium	Vlaams Brabant
Brossier	Nicole	M.D., Ph.D.	Washington University in St. Louis	USA	Missouri
Browder	Vidya	Ph.D.	Children's Tumor Foundation	USA	New York
Cai	Wenli	Ph.D.	Massachusetts General Hospital	USA	Massachusetts
Campen	Cynthia	M.D.	Stanford University	USA	California
Cannon	Ashley	Ph.D.	University of Alabama at Birmingham	USA	Alabama
Carbonell	Amanda	R.N.	National Cancer Institute	USA	Maryland
Carnaby	Jeanne	R.N., M.S.	AstraZeneca	USA	Nebraska
Carnes	Rachel	Student	University of Alabama at Birmingham	USA	Alabama
Castellanos	Elisabeth	Ph.D.	IGTP - CAMPUS CAN RUTI	Spain	Barcelona
Catasus Segura	Nuria	M.D.	IGTP - CAMPUS CAN RUTI	Spain	Barcelona
Caterina	Michael	M.D., Ph.D.	Johns Hopkins School of Medicine	USA	Maryland
Chagnon	Sarah	M.D.	Children's Specialty Group	USA	Virginia
Chang	Long-Sheng	Ph.D.	Abigail Wexner Research Inst., Nationwide Children's Hospital / The Ohio State University	USA	Ohio
Chang	Eric	Ph.D.	Baylor College of Medicine	USA	Texas
Chen	Zhiguo	M.D., Ph.D.	UT Southwestern Medical Center	USA	Texas
Cho-rohlfen	Mimi	M.D., Ph.D.	Dermatology specialists	USA	Minnesota
Christen	Jayne	Ph.D.	Leidos	USA	Maryland
Cohen	Tammy		Rimma Sherman, M.D. PC.	USA	New Jersey
Cohen	Julia	M.D.	Pediatric Oncology Branch/National Institutes of Health	USA	Maryland
Collins-Sawaragi	Yoshua	M.D.	Guy's and St Thomas' NHS Foundation Trust	United Kingdom	Lambeth
Considine	Timothy		Recursion Pharmaceuticals	USA	Utah
Cota	Bruno César	M.D.	Neurofibromatosis Reference Center of the Federal University of Minas Gerais	Brazil	Minas Gerais
Craigien	William	M.D., Ph.D.	Baylor College of Medicine	USA	Texas
Creus	Edgar	M.S.	ICO - IDIBELL Catalan Institute of Oncology	Spain	Barcelona
Crocker	Laura		Ashfield Healthcare Communications	United Kingdom	Cheshire
Cunningham	Tracy	M.D.	AstraZeneca	United Kingdom	Cambridgeshire
Dabscheck	Gabriel	M.D.	Royal Children's Hospital	Australia	Victoria
Daldrup	Heike	M.D., Ph.D.	Stanford University	USA	California
Dave	Foram	Student	University of Plymouth	United Kingdom	Devon
Davis-Keppen	Laura	M.D.	Sanford University of South Dakota School of Medicine	USA	South Dakota
de Blank	Peter	M.D.	Cincinnati Children's Hospital Medical Center	USA	Ohio
Dekker	Saskia		Stichting Neurofibromatose	Netherlands	Noord-Holland
del Castillo	Allison	Student	Children's National Health System	USA	District of Columbia
Derdak	Joanne	R.N., CPNP	National Cancer Institute	USA	Maryland
DeSanto	Jennifer	R.N.	NIH	USA	Maryland
Deyle	David	M.D.	Mayo Clinic	USA	Minnesota
Dhamija	Radhika	M.D.	mayo clinic	USA	Arizona
Dobrea	Lavinia	M.S.	AstraZeneca	USA	California
Dodd	Rebecca	Ph.D.	University of Iowa	USA	Iowa
Doergeloh	Beate Barbara	M.D.	Hanover Medical School, Hanover, Germany	Germany	Lower-Saxony
Dombi	Eva	M.D.	National Institutes of Health	USA	Maryland
Dompierre	Jessica	R.N.	NIH, National Cancer Institute, Pediatric Oncology Branch	USA	Maryland
Dong	Xinzhong	Ph.D.	Johns Hopkins University School of Medicine	USA	Maryland
Doser	Karoline		Danish Cancer Society	Denmark	København
Doshi	Dipam		Springworks Therapeutics	USA	California
Draper	Garrett	Student	University of Minnesota	USA	Minnesota

PARTICIPANTS

Attendees List – 2019 NF Conference

LAST NAME	FIRST NAME	SUFFIX	COMPANY	WORK COUNTRY	WORK STATE
Dufek	Anne	R.N., CPNP	National Institutes of Health	USA	Maryland
Duplain-Laferriere	Frédérique	Student	Université de Sherbrooke	Canada	Québec
Dyson	Alex	Student	University of Manchester	United Kingdom	Greater Manchester
Ehara	Yuko	M.D.	Tottori University Hospital	Japan	Tottori
Elkin	Zachary	M.D.	NYU Langone Eye Center	USA	New York
Engel	Julie	R.N.	Cardinal Glennon Children's Hospital	USA	Missouri
Engelson	Celia	R.N., M.S.	NYU Langone Health	USA	New York
Evans	D Gareth	M.D., Ph.D.	University of Manchester	United Kingdom	Manchester
Everson	Richard	M.D.	UCLA	USA	California
Farouk Sait	Sameer	M.D.	Memorial Sloan Kettering Cancer Center	USA	New York
Feng	Ying	M.S.	Vivace Therapeutics	USA	California
Fernandez Rodriguez	Juana	Ph.D.	IDIBELL	Spain	Barcelona
Ferner	Rosalie	M.D.	Guy's and St. Thomas' NHS Foundation Trust	United Kingdom	London
Field	Jeffrey	Ph.D.	University of Pennsylvania/Perelman School of Med	USA	Pennsylvania
Finamore	Lauren	R.N., M.S.	Seattle Children's Hospital	USA	Washington
Fisher	Laura	M.S., CGC	Mayo Clinic	USA	Minnesota
Fisher	Carla		AstraZeneca	United Kingdom	Cambridgeshire
Fisher	Michael	M.D.	Children's Hospital of Philadelphia	USA	Pennsylvania
Fitzgerald	Keely	M.D.	Children's Mercy Hospital	USA	Missouri
Flores	E'Lissa	Ph.D.	Milken Institute	USA	District of Columbia
Franklin	Barbara			USA	New Jersey
Frost	Mick	M.D.	Western Diagnostic Services Laboratory	USA	California
Fukuta	Hirota	M.D.	The Jikei University School of Medicine	Japan	Tokyo
Galloway	McKinnon		Children's Tumor Foundation	USA	North Carolina
Galloway	Tracy		CTF Board of Directors	USA	North Carolina
Gardner	Kathy	M.D.	University of pittsburgh	USA	Pennsylvania
Gazdov	Nikola		Renergy	Bulgaria	
Geller	Thomas	M.D.	Johns Hopkins All Children's Hospital	USA	Florida
George-Abraham	Jaya	M.D.	Dell Children's Medical Group	USA	Texas
Ghoshal	Pushpankur	Ph.D.	Augusta University	USA	Georgia
Giancotti	Filippo	M.D., Ph.D.	The University of Texas MD Anderson Cancer Center	USA	Texas
Ginn	Samantha	Ph.D.	Children's Medical Research Institute	Australia	New South Wales
Ginn	Kevin	M.D.	Children's Mercy Hospital	USA	Missouri
Giovannini	Marco	M.D., Ph.D.	University of California Los Angeles	USA	California
Glad	Danielle	Student	UWM Psychology Department	USA	Wisconsin
Goetsch	Allison	M.S., CGC	Lurie Children's Hospital and Feinberg School of Medicine	USA	Illinois
Gosline	Sara	Ph.D.	Sage Bionetworks	USA	Washington
Granger	Leslie	M.S., CGC	Randall Children's Hospital at Legacy Emanuel	USA	Oregon
Graup	Lisa		AstraZeneca	USA	Maryland
Greenwood	Robert	M.D.	University of North Carolina School of Medicine	USA	North Carolina
Griffin	Danielle	Student	Children's National Health System	USA	District of Columbia
Grit	Jamie	Student	Van Andel Institute	USA	Michigan
Groft	Stephen	Pharm.D.	NCATS	USA	Maryland
Gros-Louis	Francois	Ph.D.	Université Laval	Canada	Québec
Gross	Andrea	M.D.	National Institutes of Health	USA	Maryland
Guan	Kun-Liang	Ph.D.	University of California San Diego	USA	California
Gumbiner	Barry	Ph.D.	University of Washington	USA	Washington
Gupta	Punita	M.D.	St Joseph's University Medical Center	USA	New Jersey
Gutmann	David	M.D., Ph.D.	Washington University School of Medicine	USA	Missouri
Hachen	Rachel	M.D.	Children's Hospital of Philadelphia/ University of Pennsylvania	USA	Pennsylvania
Hagedorn	Caroline	R.N., CPNP	University of Utah	USA	Utah
Hahn	Cindy		Texas Neurofibromatosis Foundation	USA	Texas
HAJJAR	FOUAD	M.D.	Advent Health Orlando	USA	Florida
Halliday	Dorothy	M.D., Ph.D.	Oxford University Hospitals NHS Foundation Trust	United Kingdom	Oxfordshire
Handrup	Mette Møller	M.D., Ph.D.	Center of Rare Diseases, Aarhus University Hospital	Denmark	Århus
Harris	Allyse		Children's Hospital of The King's Daughters	USA	Virginia
Harris	Gordon	Ph.D.	Massachusetts General Hospital	USA	Massachusetts
Harrod	Virginia	M.D.	Dell Children's Medical Center	USA	Texas
Haws	Tina	R.N.	Children's Hospital Colorado	USA	Colorado
Heisey	Kara		Leido Biomedical Research	USA	Maryland
Hemenway	Molly	R.N., CPNP	Children's Hospital Colorado, Univ of Colorado	USA	Colorado
Hennigan	Robert	Ph.D.	Cincinnati Children's Hospital	USA	Ohio
Hirbe	Angela	M.D., Ph.D.	Washington University in St.Louis	USA	Missouri
Hocking	Matthew	Ph.D.	Children's Hospital of Philadelphia	USA	Pennsylvania
Horvitz	Richard		Chair, CTF Board of Directors	USA	Ohio
Hou	Yang	Ph.D.	National Cancer Institute, NIH	USA	Maryland
Huson	Susan	M.D.	Retired	United Kingdom	Greater Manchester
Ikuta	Kunihiro	M.D.	Nagoya University	Japan	Aichi
Iloeje	Uche	M.D.	SpringWorks Therapeutics	USA	Connecticut
Ilyas	Mohammed	M.D.	Children's Mercy Hospital	USA	Missouri
Jacobson	Mona	R.N., CPNP	Children's Hospital Colorado/University of Colorado	USA	Colorado
Jiang	Xuejun	Ph.D.	Memorial Sloan Kettering Cancer Center	USA	New York
Jordan	Justin	M.D.	Massachusetts General Hospital	USA	Massachusetts
Joyce	Sarah	Ph.D.	National Health Service UK	United Kingdom	London
Jung	Juliane	Ph.D.	Leibniz Institute on Aging - Fritz Lipmann Institute	Germany	
Kahler	Melissa		Cincinnati Children's Hospital	USA	Ohio
Kalamarides	Michel	M.D., Ph.D.	Neurosurgery, Hopital Pitié-Salpétrière	France	
Kallionpää	Roope	M.S.	University of Turku	Finland	
Kamei	Koji	M.D., Ph.D.	Kamei clinic	Japan	Toyama
Karajannis	Matthias	M.D.	Memorial Sloan Kettering Cancer Center	USA	New York
Kaur	Gurcharanjeet	M.D.	Alfred I. duPont Hospital for children	USA	Delaware
Keller	Bryant	Student	University of Minnesota	USA	Minnesota
Kelly-Mancuso	Geraldine	R.N.	CCHMC	USA	Ohio
Kelts	Kate	R.N.	Children's Tumor Foundation	USA	New York

PARTICIPANTS

Attendees List – 2019 NF Conference

LAST NAME	FIRST NAME	SUFFIX	COMPANY	WORK COUNTRY	WORK STATE
Kenborg	Line	Ph.D.	Danish Cancer Society	Denmark	København
Kerr	Megan-Cherise	Student	University of Greenwich	England	
Khalil	Nashwa		NYU Langone Health - Rusk Rehabilitation	USA	New York
Khanna	Rajesh	Ph.D.	Pharmacology and Neuroscience, University of Arizona	USA	Arizona
Ki	DongHyuk	Ph.D.	Dana-Farber Cancer Institute/ Harvard Medical School	USA	Massachusetts
Kim	YooRi	M.S.	Gilbert Family Foundation	USA	Michigan
Kim	Raymond	M.D., Ph.D.	Mount Sinai Hospital	Canada	Ontario
Kirk	George	Ph.D.	Astra Zeneca	United Kingdom	Cambridgeshire
Kissil	Joe	Ph.D.	The Scripps Research Institute	USA	Florida
Klein-Tasman	Bonita	Ph.D.	University of Wisconsin-Milwaukee	USA	Wisconsin
Klesse	Laura	M.D., Ph.D.	UT Southwestern	USA	Texas
Knight	Pamela	M.S.	CTF	USA	New York
Koga	Monji	M.D., Ph.D.	Fukuoka University Hospital	Japan	Fukuoka
Kohlmeyer	Jordan	Student	University of Iowa	USA	Iowa
Koneazny	Lisa	R.N.	Children's Hospital of WI	USA	Wisconsin
Korf	Bruce	M.D., Ph.D.	The University of Alabama at Birmingham	USA	Alabama
Kwatra	Shawn	M.D.	Johns Hopkins Medicine	USA	Maryland
La Rosa	Salvatore	Ph.D.	Children's Tumor Foundation	USA	New York
Langseth	Abe	Ph.D.	SpringWorks Therapeutics	USA	Maryland
Largaespada	David	Ph.D.	University of Minnesota	USA	Minnesota
Larsson	Alex		University of Minnesota	USA	Minnesota
Lascalles	Karine	M.D.	National Neurofibromatosis Service Guys and St Thomas NHS Foundation Trust, London	United Kingdom	Southwark
Lazaro	Conxi	Ph.D.	Catalan Institute of Oncology (ICO-IDIBELL)	Spain	
Le	Kim My	Student	University of Turku	Finland	
Le	Lu	M.D., Ph.D.	UT Southwestern Medical Center	USA	Texas
Lee	Beomhee	M.D., Ph.D.	Asan Medical Center	South Korea	
Lee	Kristin	M.S.	UW-Milwaukee	USA	Wisconsin
Legius	Eric	M.D., Ph.D.	UZ Leuven	Belgium	Vlaams Brabant
Lester	Ethan	Ph.D.	Massachusetts General Hospital	USA	Massachusetts
Levin	Becca	Ph.D.	Recursion Pharmaceuticals	USA	Utah
Lewis	Andrea	M.S., CGC	Baylor College of Medicine/Texas Children's Hospital	USA	Texas
Li	Veetai	M.D.	oshei children's hospital	USA	New York
Li	Shiwei	M.D.	Capital Medical University	China	Beijing
Li	Peng	M.D.	Beijing Tian Tan Hospital, Capital Medical University	China	Beijing
Li	Mo		Citicbank	China	Beijing
Lightner	Donita	M.D.	University of Kentucky	USA	Kentucky
Listernick	Robert	M.D.	Northwestern University, Feinberg School of Medicine	USA	Illinois
Liu	Pinan	M.D., Ph.D.	Beijing Tian Tan Hospital	China	Beijing
Lobbous	Mina	M.D.	University of Alabama at Birmingham	USA	Alabama
Long	Ashlee	M.S.	University of Alabama at Birmingham	USA	Alabama
Lopez	Jocelyne	Student	UCSF	USA	California
Lorenzo	Claire	Student	UCSF	USA	California
Ly	Ina	M.D.	Massachusetts General Hospital	USA	Massachusetts
Manso	Simone		CTF Board o	Switzerland	Zürich
Martikkala	Eija	Ph.D.	University of Turku, Institute of Biomedicine	Finland	
Martin Peron	Staci	Ph.D.	National Cancer Institute	USA	Maryland
Maspero	Sally	R.N.	CTF-Australia/CHW	Australia	New South Wales
Mautner	Victor-Felix	M.D.	University Medical Center Hamburg-Eppendorf, Dept. of Neurology	Germany	
Mazuelas Gallego	Helena	M.D.	IGTP	Spain	Barcelona
McDonald	Amy		Texas Tech University Health Sciences Center	USA	Texas
McGivney	Gavin	Student	University of Iowa	USA	Iowa
McMahon	Kate	R.N.	Children's Hospital Colorado	USA	Colorado
Mejia	Luz	M.S.	Canela	USA	Texas
Mejia	Rodrigo	M.D.	MD Anderson Cancer Center	USA	Texas
Merker	Vanessa	Ph.D.	Edith Nourse Rogers Memorial Veterans Hospital	USA	Massachusetts
Merkley	Tricia	R.N.	Seattle Children's Hospital	USA	Washington
Messiaen	Ludwine	Ph.D.	UAB	USA	Alabama
Miller	David	M.D., Ph.D.	Boston Children's Hospital	USA	Massachusetts
Miller	Douglas	M.D., Ph.D.	University of Missouri School of Medicine	USA	Missouri
Mills	Kristen	Ph.D.	Rensselaer Polytechnic Institute	USA	New York
Minor	Lloyd	M.D.	Stanford University School of Medicine, Dean	USA	California
Mission	Paige	Ph.D.	UW Madison Department of Neurology	USA	Wisconsin
Mo	Juan	Ph.D.	UT Southwestern Medical Center	USA	Texas
Moertel	Christopher	M.D.	University of Minnesota	USA	Minnesota
Moody	Kristen		SpringWorks Therapeutics	USA	North Carolina
Moon	Chang-In	Student	Washington University in St. Louis	USA	Missouri
Moots	Paul	M.D.	Vanderbilt University Medical Center	USA	Tennessee
Moran	Jon	Ph.D.	Ashfield Healthcare Communications	United Kingdom	Cheshire
Morin	Caroline		Gilbert Family Foundation	USA	Michigan
Morris	Stephanie		Washington University	USA	Missouri
Moutal	Aubin	Ph.D.	University of Arizona	USA	Arizona
Nanoo	Seeta	R.N., M.S.	Childrens Hospital Los Angeles	USA	California
Nghiempfu	P. Leia	M.D.	UCLA Neuro-Oncology	USA	California
Nguyen	Thien	Student	Neurology, UCLA Neuro-Oncology	USA	California
Nievo	Marco	Ph.D.	Children's Tumor Foundation	Italy	Siena
Nikrad	Julia	Student	University of Minnesota	USA	Minnesota
Nilton	Rezende	M.D.	Federal University of Minas Gerais	Brazil	Minas Gerais
Nishida	Yoshihiro	M.D., Ph.D.	Nagoya University Hospital	Japan	Aichi
O'Sullivan Coyne	Geraldine	M.D., Ph.D.	NIH/National Cancer Institute	USA	Maryland
Oban	Cheri	M.S.	NA	USA	California
Oberlander	Beverly		NF Network	USA	California
Oberlander	Lewis	Ph.D.	Neurofibromatosis Network	USA	California
Oblinger	Janet	Ph.D.	NCH Research Institute	USA	Ohio

PARTICIPANTS

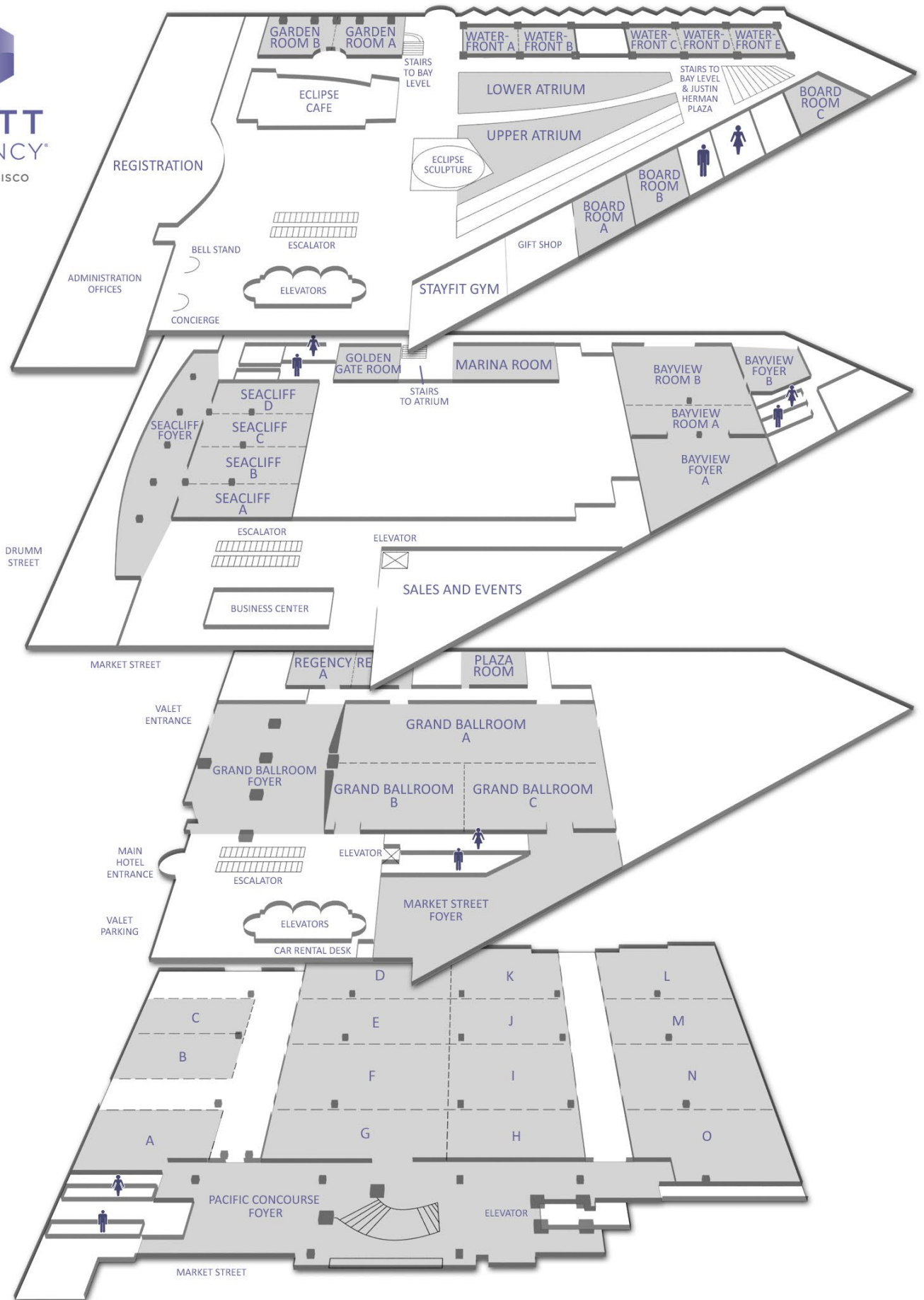
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LAST NAME	FIRST NAME	SUFFIX	COMPANY	WORK COUNTRY	WORK STATE
Ohashi	Hirofumi	M.D., Ph.D.	Division of Medical Genetics, Saitama Children's Medical Center	Japan	Saitama
Ohden	Lisa	M.S., CGC	Sanford Health	USA	South Dakota
O'Loughlin	Evan	Student	Massachusetts General Hospital	USA	Massachusetts
Oostenbrink	Rianne	M.D., Ph.D.	ErasmusMC	Netherlands	Zuid-Holland
Orden	Tony			USA	California
Orr	Christina	R.N., M.S.	Massachusetts General Hospital	USA	Massachusetts
Osborne	Kimberly		University of Kentucky - Neurology Department	USA	Kentucky
Ostrow	Kimberly	Ph.D.	Johns Hopkins University	USA	Maryland
Osum	Sara	Student	University of Minnesota	USA	Minnesota
Ota	Arihito	M.D.	Jikei University School of Medicine	Japan	Tokyo
Packer	Roger	M.D.	Children's National Medical Center	USA	District of Columbia
Pan	Yuan	Ph.D.	Stanford University	USA	California
Pancaza	Patrice		Children's Tumor Foundation	USA	New York
Panzer	Karin	M.S., CGC	University of Iowa Hospitals and Clinic	USA	Iowa
Papi	Laura	M.D., Ph.D.	University of Florence	Italy	Firenze
Parada	Luis	Ph.D.	Memorial Sloan Kettering Cancer Center	USA	New York
Pardej	Sara	Student	University of Wisconsin-Milwaukee	USA	Wisconsin
Patel	Neha	M.D.	University of Wisconsin	USA	Wisconsin
Payne	Jonathan	Ph.D.	Murdoch Children's Research Institute	Australia	Victoria
Peer	Cody	Ph.D.	National Cancer Institute	USA	Maryland
Peltonen	Juha	M.D., Ph.D.	University of Turku	Finland	
Peltonen	Sirkku	M.D., Ph.D.	University of Turku	Finland	
Piccoli	Giuseppe	Ph.D.	AstraZeneca	USA	New York
Pichard	Dominique Corinne	M.D.	National Institutes of Health, NIAMS	USA	Maryland
Piotrowski	Anna	M.D.	MSKCC	USA	New York
Plotkin	Scott	M.D., Ph.D.	Massachusetts General Hospital	USA	Massachusetts
Pond	Dinel	M.S., CGC	Children's Minnesota	USA	Minnesota
Post	Leonard	Ph.D.	Vivace Therapeutics	USA	California
Powala	Christopher		NFlection Therapeutics, Inc.	USA	Pennsylvania
Poyhonen	Minna	M.D., Ph.D.	Dept of Clinical Genetics, Helsinki University Hospital	Finland	
Prada	Carlos	M.D.	Cincinnati Children's Hospital Medical Center	USA	Ohio
Pratilas	Christine	M.D.	Johns Hopkins University	USA	Maryland
Pride	Natalie	Ph.D.	The Children's Hospital at Westmead	Australia	New South Wales
Puccetti	Diane	M.D.	American Family Children's Hospital, University of Wisconsin-Madison	USA	Wisconsin
Quelle	Dawn	Ph.D.	University of Iowa	USA	Iowa
Radtke	Heather	M.S., CGC	Medical College of Wisconsin and Children's Tumor Foundation	USA	New York
Rai	Puneet	M.S., CGC	Oregon Health & Science University	USA	Oregon
Ramirez	Erika	R.N.	Washington University	USA	Missouri
Ratner	Nancy	Ph.D.	Cincinnati Children's Hospital	USA	Ohio
Rauen	Kate	M.D., Ph.D.	University of California Davis	USA	California
Reddy	Alyssa	M.D.	University of California San Francisco	USA	California
Reilly	Karlyne	Ph.D.	NCI, NIH	USA	Maryland
Rhodes	Steven	M.D., Ph.D.	Indiana University School of Medicine/Riley Hospital for Children	USA	Indiana
Riccardi	Vic	M.D.	The Neurofibromatosis Institute	USA	California
Rice	Frank	Ph.D.	Integrated Tissue Dynamics LLC	USA	New York
Rios	Jonathan	Ph.D.	Texas Scottish Rite Hospital for Children	USA	Texas
Robinson	J. Elliott	M.D., Ph.D.	California Institute of Technology	USA	California
Röhl	Claas		NF Kinder / NF Patients United	Austria	Wien
Romo	Carlos	M.D.	Johns Hopkins Hospital	USA	Maryland
Rosenbaum	Thorsten	M.D.	Sana Kliniken Duisburg	Germany	
Rosenmayr	Verena	Student	Medical University of Vienna / Department for Pediatrics and Adolescent Medicine	Austria	Wien
Rosser	Tena	M.D.	Children's Hospital Los Angeles	USA	California
Rowe	Ashley		University Hospitals- Rainbow Babies & Childrens	USA	Ohio
Roy	Vincent	Student	Université Laval/LOEX	Canada	Québec
RUBINSTEIN	C DUSTIN	Ph.D.	Biotechnology Center/University of Wisconsin	USA	WI
Rukin Gold	Deborah	M.D.	Rainbow Babies & Children's Hospital	USA	Ohio
Sandelin	Martin	M.D., Ph.D.	AstraZeneca	Sweden	
Sankaran	Hari	M.D.	National Institute of Health	USA	Maryland
Sarnoff	Herb		Inflix Bioscience, Inc.	USA	California
Sato	Aimee	M.D.	Seattle Children's	USA	Washington
Schatz	Krista	M.S., CGC	Johns Hopkins University Department of Genetic Medicine	USA	Maryland
Schindeler	Aaron		The Children's Hospital at Westmead	Australia	New South Wales
Schorry	Elizabeth (Betty)	M.D.	Cincinnati Children's Hospital Medical Center	USA	Ohio
Seidlin	Mindell	M.D.	Seidlin Consulting LLC	USA	New York
Serra	Eduard	Ph.D.	Program on Hereditary Cancer	Spain	Barcelona
SHAH	NIDHI	M.D.	Penn State Health	USA	Pennsylvania
Shanmuganayagam	Dhanu	Ph.D.	University of Wisconsin-Madison	USA	Wisconsin
Shannon	Kevin	M.D.	University of California San Francisco	USA	California
SHARMA	SHEEL	M.D.	NYU Langone Hospital	USA	New York
Shea, PA-C	Stephanie		Children's Hospital Colorado	USA	Colorado
Sheerin	Una-Marie	Ph.D.	Guy's and St Thomas' Hospital NHS Trust	United Kingdom	London
Sherman	Larry	Ph.D.	Oregon Health & Science University	USA	Oregon
Sherman	Rimma	M.D.	Rimma Sherman M.D. PC.	USA	New Jersey
Shulkin	Oleg		AstraZeneca Germany GmbH	Germany	
Siqveland	Elizabeth	R.N., CPNP	Children's - Minnesota	USA	Minnesota
Smith	Miriam	Ph.D.	University of Manchester	United Kingdom	Manchester
Smith	Abbi		Indiana University, School of Medicine	USA	Indiana
Smith	Katie	R.N.	Children's Hospital of Philadelphia	USA	Pennsylvania
So	Karen	M.D.	AstraZeneca	United Kingdom	Cambridgeshire
Soll	Richard	Ph.D.	WuXi AppTec	USA	Massachusetts
Sommer	Kathy	R.N., M.S.	University of Minnesota	USA	Minnesota
Song	Young-Bin		Alvord Brain Tumor Center, University of Washington Medical Center	USA	Washington
Steensma	Matthew	M.D.	Spectrum Health/Helen DeVos Children's Hospital; Van Andel Institute	USA	Michigan
Stevenson	David	M.D.	Stanford University	USA	California

PARTICIPANTS

Attendees List – 2019 NF Conference

LAST NAME	FIRST NAME	SUFFIX	COMPANY	WORK COUNTRY	WORK STATE
Sun	Daochun	Ph.D.	Memorial Sloan Kettering Cancer Center	USA	New York
Sverak	Pavlina	M.D.	University of Minnesota	USA	Minnesota
Swier Mosher	Vicki	Ph.D.	Sanford Research	USA	South Dakota
Tamula	Mary Anne	M.S.	Leidos Biomedical Research	USA	Maryland
Tang	Tracy	Ph.D.	Vivace Therapeutics	USA	California
Tang	Vivian	M.D.	Royal Manchester Children's Hospital	United Kingdom	Greater Manchester
Taylor	Stephanie	Ph.D.	Veterans Administration	USA	California
Teranishi	Yu	M.D., Ph.D.	Department of Neurosurgery, Faculty of Medicine, The University of Tokyo, Japan	Japan	Tokyo
Thain	Lisa	M.D.	Southlake Regional Health Centre	Canada	Ontario
Thain	Emily	M.S., CGC	University Health Network	Canada	Ontario
Thomas	Mary	R.N.	Guy's and St Thomas' Foundation Trust	United Kingdom	London
Thompson	Heather	Ph.D.	California State University, Sacramento	USA	California
Tongsgard	James	M.D.	University of Chicago	USA	Illinois
Traber	Jennifer		Washington University in St. Louis	USA	Missouri
tran	nam	M.D.	Moffitt Cancer Center	USA	Florida
Trapane	Pamela	M.D.	UF College of Medicine – Jacksonville	USA	District of Columbia
Tremblay	Danny	M.S.	CHUM	Canada	Québec
Tritz	Rebekah	M.S.	Augusta University - Vascular Biology Center	USA	Georgia
Truitt	Morgan	Ph.D.	The Salk Institute for Biological Studies	USA	California
Tschiffely	Anna	Ph.D.	Ripple Effect Communications, CDMRP	USA	Maryland
Tsui	Karen	M.D.	Starship Children's Hospital	New Zealand	
Tumminello	Brad		SpringWorks Therapeutics	USA	Texas
Tydings	Caitlin	M.D.	Children's National Medical Center	USA	District of Columbia
Ullrich	Nicole	M.D., Ph.D.	Boston Children's Hospital	USA	Massachusetts
Uy	Ryan	M.D.	Children's National Medical Center	USA	District of Columbia
Vaassen	Pia	M.D.	Sana Kliniken Duisburg GmbH	Germany	
van Minkelen	Rick	Ph.D.	Erasmus Medical Center	Netherlands	Zuid-Holland
Vassallo	Grace	M.D.	Complex NF1 service	United Kingdom	Manchester
Vasudevan	Harish	M.D., Ph.D.	University of California San Francisco	USA	California
Verma	Sharad	Ph.D.	Johns Hopkins	USA	Maryland
Vishwanathan	Karthick	Ph.D.	AstraZeneca	USA	Massachusetts
Viskochil	David	M.D., Ph.D.	University of Utah	USA	Utah
Vitte	Jeremie	Ph.D.	UCLA	USA	California
Vogt	Daniel	Ph.D.	Michigan State University	USA	Michigan
Vukelj	Simon		Children's Tumor Foundation	USA	New York
Walker	James	Ph.D.	MGH Center for Genomic Medicine	USA	Massachusetts
Wallace	Peggy	Ph.D.	University of Florida	USA	Florida
Wallis	Deeann	Ph.D.	University of Alabama at Birmingham	USA	Alabama
Walsh	Karin	Ph.D.	Children's National Health System	USA	District of Columbia
Walter	Joe		AstraZeneca	USA	Maryland
Wang	Xia	M.D., Ph.D.	Moffitt Cancer Center	USA	Florida
Wang	Wenqi	Ph.D.	University of California, Irvine	USA	California
Watson	Adrienne	Ph.D.	Recombinetics Inc.	USA	Minnesota
Weber	Mike		SpringWorks Therapeutics	USA	North Carolina
Wegscheid	Michelle	Student	Washington University School of Medicine in St. Louis	USA	Missouri
Weimer	Jill	Ph.D.	Sanford Research	USA	South Dakota
Weiss	Brian	M.D.	Cincinnati Children's Hospital and Medical Center	USA	Ohio
Welling	D. Bradley	M.D., Ph.D.	Massachusetts Eye and Ear	USA	Massachusetts
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White	Katie		Sanford Research	USA	South Dakota
Widemann	Brigitte	M.D.	National Institutes of Health	USA	Maryland
Williams	Kyle	Ph.D.	University of Minnesota	USA	Minnesota
Williams	Danaia		Children's Tumor Foundation	USA	New York
Wind Mitchell	Carole	R.N., M.S.	NYU Langone Health	USA	New York
Wirtanen	Tracy	M.S.	Littlest Tumor Foundation	USA	Vermont
Wolf	Heather	M.D.	Kaiser	USA	California
Wolkenstein	Pierre	M.D., Ph.D.	Henri-Mondor Hospital, UPEC, AHPH, Créteil, France	France	France
Wolters	Pamela	Ph.D.	National Cancer Institute	USA	Maryland
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Woods	Dennis		Exelixis	USA	Tennessee
Wootton	Michael		NF2 Therapeutics, Inc.	USA	Massachusetts
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Yates	Charles	M.D.	Indiana University	USA	Indiana
Yi	Chunling	Ph.D.	Georgetown University Medical Center	USA	District of Columbia
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Yoshinaga	Akiko	M.D.	Kyoto University Hospital	Japan	Kyoto
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Yu	Yanan	Student	University of California San Francisco	USA	Ohio
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Zhao	Fu	M.D., Ph.D.	Beijing Tian Tan Hospital	China	Beijing
Zhong	Yan		Shenzhen Neurofibromatosis (NF) Care Centre	China	Guangdong
Zhou	Jiangbing	Ph.D.	Yale University	USA	Connecticut
Zhou	Chengming		Government	China	Beijing
Zhu	Yuan	Ph.D.	Childrens National Medical Center at Washington DC	USA	District of Columbia
Ziegler	Natalie	R.N., CPNP	House Ear Institute	USA	California



Local Area Dining Options

Embarcadero 1

- @Fuzio Universal Bistro
- *Gambino's NY Subs
- #The Melt
- *Thrive Juicery

Embarcadero 2

- *Anderson's Bakery
- #Blanc et Rouge Wine Bar
- @Blue Hawaii Acai Café
- @Gochees Pizza
- *Proper Food
- @Peet's Coffee

Embarcadero 3

- *Green Bar
- #Kirimachi Ramen
- *Pressed Cafe

Embarcadero 4

- @Boudin Sourdough Bakery
- #Breaking Bread Sandwiches
- #Buckhorn Grill
- @SOSHA Thai Restaurant
- @Over the Moon
- @Posh Bagel
- #Rubio's Fresh Mex Grill
- #Ssens Restaurant
- #Stone Korean Kitchen
- @Crystal Jade
- *Ladel & Leaf
- *5th Ave. Deli & Market

Ferry Building

- @American Eatery
- #Bouli Bar
- @Boulettes Larder (Closed Monday)
- @Cowgirl Sidekick Café
- @Delica
- @Golden Gate Meat Co
- Farmer's Market (Tu, Th, Sa)
- @Sow Juice

@\$Gotts Roadside

@Hog Island Oyster Co

@El Porteno

@Mijita

@Out the Door

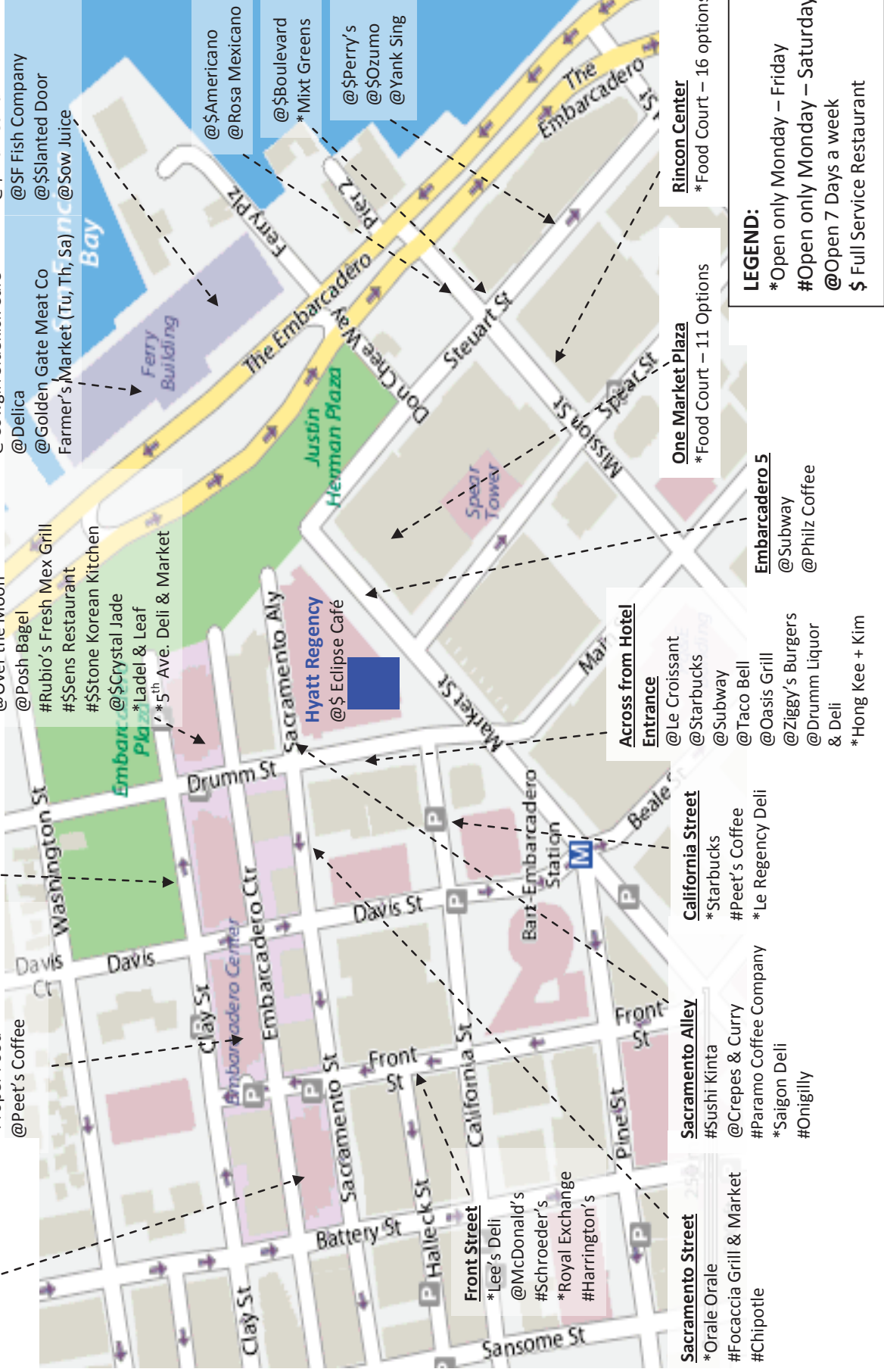
@Prather Ranch Meat Co

@\$Market Bar

@SF Fish Company

@\$Slanted Door

@Sow Juice



@\$Americano
@Rosa Mexicano

@\$Boulevard
*Mixt Greens

@\$Pherry's
@\$Ozumo
@Yank Sing

Rincon Center
*Food Court – 16 options

One Market Plaza
*Food Court – 11 Options

LEGEND:

- *Open only Monday – Friday
- #Open only Monday – Saturday
- @Open 7 Days a week
- \$ Full Service Restaurant

Embarcadero 5

- @Subway
- @Philz Coffee

Across from Hotel Entrance

- @Le Croissant
- @Starbucks
- @Subway
- @Taco Bell
- @Oasis Grill
- @Ziggy's Burgers
- @Drumm Liquor & Deli
- *Hong Kee + Kim

California Street

- *Starbucks
- #Peet's Coffee
- *Le Regency Deli

Sacramento Alley

- #Sushi Kinta
- @Crepes & Curry
- #Paramo Coffee Company
- *Saigon Deli
- #Onigilly

Sacramento Street

- *Orale Orale
- #Focaccia Grill & Market
- #Chipotle

Front Street

- *Lee's Deli
- @McDonald's
- #Schroeder's
- *Royal Exchange
- #Harrington's

SAVE THE DATE



CHILDREN'S
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2020
NF CONFERENCE
JUNE 13 - 16, 2020

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Juha Peltonen, MD, PhD, University of Turku, Finland

Jill Weimer, PhD, Sanford Research

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