



PROGRESS THROUGH PARTNERSHIP

THE NINDS 2023
NONPROFIT FORUM
JULY 24-25, 2023



National Institute of
Neurological Disorders
and Stroke

First Name	Last Name	Organization
Salewa	Akintilo	Association for Research in Vision and Ophthalmology (ARVO)
Aimee	Alcott	National Ataxia Foundation
Kim	Anderson	NASCIC
Diana	Andriola	NINDS
Kyra	Ange	The NeurolImpact Foundation
Sue	Ano	NINDS
Roger	Arko	Caretaker
Ram	Arudchandran	NINDS
Debra	Babcock	NINDS
Julia	Bachman	NIH/NINDS
Chinmayi	Balusu	Simply Neuroscience
Linda	Bambrick	NINDS
Amy	Bany Adams	NIH/NINDS
Marco	Baptista, PhD	Christopher & Dana Reeve Foundation
Elena	Barnaeva	NINDS
Ronald	Bartek	Friedreich's Ataxia Research Alliance (FARA); NCATS Alliance
Kimberly	Beer	Christopher & Dana Reeve Foundation
Ramona	Belfiore-Oshan	Critical Path Institute
Emily	Bell	Bow Foundation
Daniel	Bello	NINDS
Janna	Belser-Ehrlich	NIH
Wanda	Benjamin	Nonprofit
Richard	Benson	NIH-NINDS
Shyama	Bhatt	NINDS
Victoria	Bitzer-Wales	NINDS
Geraldine	Bliss	CureSHANK
Naomi	Booker	NINDS
Nicole	Boschi	National Multiple Sclerosis Society
Francesca	Bosetti	NINDS
Chris	Boshoff	NINDS
Pam	Bower	Multiple System Atrophy Coalition
Beth	Bowerman	National Ataxia Foundation
Brigid	Brennan	FARA
Rich	Brennan	The ALS Association
Lynn	Brielmaier	ALS Problem Solvers
Vicki	Brings	NINDS



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First Name	Last Name	Organization
Kia	Brooks	NINDS
Jennifer	Brummet	CurePSP
Melissa	Bryce	The Global Foundation for Peroxisomal Disorders
Allison	Bulat	Northeast ALS Consortium (NEALS)
Samantha	Bureau	Concussion Legacy Foundation
Caitlin	Burgdorf	NIMH
Jenny	Burke	The FamilieSCN2A Foundation
Ian	Burkhart	North American Spinal Cord Injury Consortium
Ryan	Calabrese	NINDS
Michelle	Campbell	US FDA
Casey	Cappelletti	Academy for Radiology & Biomedical Imaging Research
Laura	Carrillo	Critical Path Institute - Critical Path for Parkinson's
Elizabeth	Cassidy	TSC ALLIANCE
Vicky	Cattani	Parkinson's Foundation
Stacey	Chambers	NIH/NINDS
Andrew	Chen	NINDS
Deepa	Chhatwal	IQ Solutions Inc.
Sophie	Cho	NINDS
Severn	Churn	NINDS
Gabrielle	Conecker	Decoding Developmental Epilepsies
Christopher	Conrad	NINDS
Jessica	Corley	NINDS
Rod	Corriveau	NINDS
Michaela	Cortes	National Institute of Neurological Disorders and Stroke
Terrie	Cowley	The TMJ Association
Devon	Crawford	NINDS
Phil	Cronin	Francis, Edward, & Cronin, Inc
Penny	Dacks	AFTD
William	Daley	NINDS
Farrah	Daly	International Neuropalliative Care Society
Austin	Davis	Academy for Radiology & Biomedical Imaging Research
Polly	Dawkins	Davis Phinney Foundation
Martina	De Majo	Synapticure
Michele	Dean	NINDS
Alexander	Denker	NINDS
Yssa	DeWoody	Ring14 USA



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First Name	Last Name	Organization
Susan	Dickinson	The Association for Frontotemporal Degeneration
Damon	DiSabato	NINDS
Tracy	Dixon-Salazar	Lennox-Gastaut Syndrome (LGS) Foundation
Sara	Dodson	NINDS
Kit	Donohue	Chelsea's Hope Lafora Children Research Fund
Argenia	Doss	Government
Monica	Dudley-Weldon	Syngap1 Foundation
Oksana	Dukhanina	NINDS, NIH
Jaclyn	Durkin	National Institute for Neurological Disorders and Stroke
Brian	DuVal	Hemophilia Federation of America
Gustavo	Dziewczapolski	Cure CMD and AFBS
Nancy	Eaby	NINDS
Brian	Entzminger	Deloitte
Kaitlyn	Esposito	Bobby Jones Chiari & Syringomyelia Foundation
Christina	Fang	NIH
Carlos	Faraco	NINDS
Nicole	Farhat	NIH/NINDS
Wendy	Faust	Live Like Lou Foundation
Diana	Felner	Tourette Association of America
Claudia	Figueroa-Romero	NIH
Aliza	Fink	National Organization for Rare Disorders
A. Reghan	Foley	NINDS, NIH
Jane	Fountain	NIH/NINDS
Jacqueline	French	Epilepsy Foundation
Laura	Freveletti	Les Turner ALS Foundation
Maynard	Friesz	Cure SMA
Patrick	Frost Bellgowan	NIH/NINDS
Brandy	Fureman	Epilepsy Foundation
Alissa	Gallagher	NINDS
Shannon	Garnett	NIH/NINDS
Amanda	Garzon	Hydrocephalus Association
Mara	Gervais	SHINE Syndrome Foundation
Rebecca	Gilbert	American Parkinson Disease Association
Annette	Gilchrist	NINDS Small Business Program
Jordan	Gladman	NINDS/NIH
Amanda	Gleixner	The Association for Frontotemporal Degeneration



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First Name	Last Name	Organization
James	Goss	STXBP1 Foundation
Heidi	Grabenstatter	International Foundation for CDKL5 Research
Anne	Gramiak	American Epilepsy Society
Amy	Gray	Undiagnosed Diseases Network Foundation
Diana	Gray	Hydrocephalus Association
Caitlin	Grzeskowiak	Epilepsy Foundation
Amelie	Gubitz	NINDS
Mai	Habib	NINDS-OBD
Joseph	Hall	NINDS
Alycia	Halladay	Alliance for the Genetic Etiologies of Neurodevelopmental Disorders and Autism
Kristi	Hardy	NINDS
Nicole	Harmon	Cohen Veterans Bioscience Inc
Thomas	Hart	Critical Path Institute
Adam	Hartman	NINDS/NIH
Christi	Hayes	NIH, NINDS
Janet	He	NIH
JayEtta	Hecker	International SCN8A Alliance/ DEE-P Connections
John	Heiss	NINDS
Michele	Herndon	The Mitchell and Friends Foundation
Tish	Hevel	The Brain Donor Project
Janet	Hieshettter	Dystonia Medical Research Foundation
Kimberly	Hindery	Child Neurology Foundation
Veronica	Hood	Dravet Syndrome Foundation
Silvina	Horovitz	NINDS
Nina	Hsu	NIH/NINDS
Jianbo	Hu	Angioma Alliance
Kim	Hunter-Schaedle	Independent/Self-Employed
Grace	Hwang	NIH
Lyn	Jakeman	NINDS
David	Jett	ONETOX, NINDS, NIH
Kevin	Jones	National Institutes of Health
Maria	Kefalas	Cure MLD
Angela	Kennedy	IQVIA
Melissa	Kennedy	International Rett Syndrome Foundation
Olivia	Kent	NINDS



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First Name	Last Name	Organization
Noam	Keren	NINDS
Laura	Kimberly	NINDS
Karen	King	End the Legacy
Rebecca	King	Hypersomnia Foundation
Melody	Kisor	Cure LBSL
Naomi	Kleitman	Craig H. Neilsen Foundation
Yasmin	Kloth	NINDS/OBD
Walter	Koroshetz	NINDS
Svetlana	Kotliarova	NINDS
Ellen	Kuo	Faseb
Harry	Kwon	NINDS
Jason	Langheier	Synapticure, Foodsmart
Melissa	Lavasanian	Psychedelic Medicine Coalition
Kevin	Lenaburg	Clusterbusters
Anne	Lennox	Myotubular Trust
Jennifer	Levy	Coalition to Cure Calpain 3
Travis	Lewis	Prevail Therapeutics a wholly owned subsidiary of Eli Lilly and Company
Nina	Lichtenberg	NIH
Hao	Lin	University of Minnesota
Joe	Lindahl	The Multiple System Atrophy Coalition
Erica	Littlejohn	NIH
Jennifer	Long	NIH
Michelle	Lorenz	Voices for ALS
Laura	Lubbers	CURE Epilepsy
Dina	Lyon	NIH
Kellyn	Madden	FARA
Lake	Majestic	American Heart Association
Sunita	Malepati	CACNA1A Foundation
Laura	Mamounas	NINDS/NIH
Lisa	Manaster	CACNA1A Foundation, Inc.
Heidi	Matos	NINDS
Heidi	Matos Galicia	NINDS
Michelle	Maxwell	American Academy of Neurology
MEgan	May	Michael J. Fox Foundation
Louis	Mazawey	Foundation for Peripheral Neuropathy



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First Name	Last Name	Organization
Meghan	McAnally	NINDS
Keith	McArthur	CureGRIN Foundation
Amber	McCartney	NINDS
Linda	McGavern	NINDS
Ambereen	Mehta	Johns Hopkins School of Medicine
Carolina	Mendoza-Puccini	NINDS
Mary Anne	Meskis	Dravet Syndrome Foundation
Danny	Miller	MEPAN Foundation
Ilene	Miller	Rare Epilepsy Network
Timothy	Miller	Washington University in St. Louis School of Medicine
Carrie	Milliard	FTD Disorders Registry
Laura	Mitic	Bluefield Project to Cure FTD
DP	Mohapatra	NINDS
Caitlin	Monette	Friedreich's Ataxia Research Alliance
Stephanie	Monroe	UsAgainstAlzheimers.org
Jill	Morris	NINDS
Robert	Moss	Seizure Tracker LLC
Barry	Munro	North American SCI Consortium
Leah	Myers	FamilieSCN2A Foundation
Josh	Nadeau	Tourette Association of America
Debra	Niehoff	The Association for Frontotemporal Degeneration
Cristina	Nigro	NINDS
Michelle	Norton	American Epilepsy Society
Glen	Nuckolls	NINDS
Lori	Nusbaum	The CJD Foundation
Kimberly	Nye	TESS Research Foundation
Joan	Ohayon	NINDS
Sandra	Ojeda	Glut1 Deficiency Foundation
Katie	O'Keefe	Critical Path Institute
Rotem	Orbach	NINDS/NIH
Jiaqi	O'Reilly	National Institute of Neurological Disorders and Stroke (NIH)
Michael	Oshinsky	NINDS
Laura	Palmer	SHINE Syndrome Foundation
Jessica	Palmeri	Spina Bifida Association
Patricia	Parraguez	CIAMA
Andrea	Pauls Backman	ALS Strategy Consulting



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Michael	Pearlmutter	Cerebral Palsy Alliance Research Foundation
Michele	Pearson	BRAIN
Tony	Pearson	Eli Lilly
Mary	Pelleymounter	NINDS
Marlene	Peters-Lawrence	NINDS
Valerie	Pieraccini	United Cerebral Palsy of Central Arizona
Betsy	Pilon	Hope for HIE
Natacha	Pires	APBD Research Foundation
Terry	Pirovolakis	CureSPG50 / Elpida Therapeutics
Dorothy	Poppe	Bobby Jones Chiari & Syringomyelia Foundation
Mary	Poppe	Bobby Jones Chiari & Syringomyelia Foundation
Abigail	Potticary	NNDCS
Rebecca	Price	NINDS
Brandi	Privitera	Support Fibromyalgia Network
Shamsi	Raeissi	NINDS
Vasiliki	Rahimzadeh	Baylor College of Medicine
Myriam	RAI	FARA
Manish	Raisinghani	Target ALS Foundation, Inc.
Srikanth	Ranganathan	NINDS
Yogendra	RaoI	NINDS, Epilepsy Therapy Screening Program
Gopa	Raychaudhuri	Center for Biologics Evaluation and Research (CBER), US FDA
Alva	Recinos	NIH/NINDS/DCR
Robert	Riddle	NINDS
Asia	Rivers	Morehouse School of Medicine
Steven	Roberds	TSC Alliance
Katherine	Roche	NINDS
Chris	Rogers	Dandy Walker Alliance, Inc.
Emily	Rogers	Hydrocephalus Association
Becky	Roof	National Institute of Neurological Disorders and Stroke
Jachinta	Rooney	NINDS
Andrew	Rosen	National Ataxia Foundation
Sharyn	Rossi	BrightFocus Foundation
Cynthia	Rothblum-Oviatt	FDA
Cheryse	Sankar	NINDS/NIH
Lumy	Sawaki-Adams	NIH/NINDS
Joel	Saydoff	NINDS



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First Name	Last Name	Organization
Kristin	Schneeman	Milken Institute
Gretchen	Scott	NIH/NINDS/DCR
Shawna	Scully	Emergence Health Network
Nadia	Sethi	ALS TDI
Bina	Shah	Project 8p Foundation
Margot	Shanahan	Project ALS
Shalini	Sharma	NINDS
Angela	Sharpe	American Psychological Association
Frank	Shewmaker	NINDS
Arvind	Shukla	NINDS
Beth-Anne	Sieber	NINDS
Tjerignimin	Silue	NINDS
Courtney	Silverthorn	Foundation for the NIH
Hayla	Sluss	Non profit
Ariane	Soldatos	NINDS
Bair	Srivastav	Alliance for Headache Disorders Advocacy
Glenna	Steele	Glut1 Deficiency Foundation
Diane	Stephenson	Critical Path Institute
Sheila	Stern	American Brain Coalition
Evelyn	Stevens	Parkinson's Foundation
Lauren	Stiles	Dysautonomia International
Kate	Still	Phelan-McDermid Syndrome Foundation (PMSF)
Shawna	Strickland	American Epilepsy Society
Sara	Struwe	Spina Bifida Association
Preeti	Subramanian	BrightFocus Foundation
Tao	Sun	NINDS
Maripierre	Surpris	NINDS
Christine	Swanson-Fischer	NINDS
Jean	Swidler	Genetic ALS & FTD: End the Legacy
Elizabeth	Sypek	NINDS
Melissa	Talwar	SUPPORT FIBROMYALGIA NETWORK
Amir	Tamiz	Division of Translational Research
Cristina	Tang	Weston Family Foundation
Emily	Taylor	Solve M.E.
James	Taylor	NINDS/NIH
Susan	Taylor Brown	USAWG



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Carol	Taylor-Burds	NINDS
Sara	Te	Decoding Developmental Epilepsies
Lacey	Teal	Alliance for Patient Access
Julia	Terrell	The Sturge-Weber Foundation
Neil	Thakur	The ALS Association
Pierre	Theodore	GNE
Shruthi	Thomas	NIH NINDS
Joshua	Todd	National Institute of Neurological Disorders and Stroke, NIH
Christine	Torborg	NINDS/NIH
Kelsey	Trace	National Ataxia Foundation
Amy	Tsou	NIH
Christy	Turtzo	NIH/NINDS
George	Umanah	NIH-NINDS
Nsini	Umoh	NINDS/NIH
Brandi	Underwood	Facial Pain Association
Julienne	Verdi	Alliance for Headache Disorders Advocacy
Louise	Vetter	Huntington's Disease Society of America
Mark	Vieth	CRD Associates (representing the Foundation for Peripheral Neuropathy)
David	Voccolla	IQVIA
Vanessa	Vogel-Farley	Global Genes
Christine	Von Raesfeld	People With Empathy
Samuel	Wakelin	NINDS/Georgetown University School of Medicine
Heidi	Wallis	Association for Creatine Deficiencies
Dara	Wambach	Janssen
Erin	Ward	MTM-CNM Family Connection
Rayneisha	Watson	Deloitte Healthcare
Lauren	Webb	Les Turner ALS Foundation
Alexandra	Weiss	IQVIA
Deborah	Westphal	Karen Toffler Charitable Trust
Vicky	Whittemore	NIH/NINDS
Amy	Wickstrom	American Migraine Foundation
Nikki	Win	Genentech
Alexandria	Wise	Genentech
Sarah	Woller	NINDS
Ling	Wong	NINDS



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First Name	Last Name	Organization
Nora	Wong	NORSE Institute
Alynda	Wood	NINDS
Clinton	Wright	National Institutes of Health
Guangying	Wu	NIH/NINDS
Debbie	Yobs	CJD Foundation
Cassidy	Young	Alliance for Headache Disorders Advocacy
Jane	Zeender	Pediatric Epilepsy Research Consortium