

## Letter to CIRM

June 2024

To: CIRM Board of Directors and governing bodies

Subject: CIRM Future Funding of Rare Genetic Disorders

We are California-based patient advocacy organizations, researchers, clinicians and drug developers. We represent a large group of California taxpayers who also are stakeholders in the development of therapies for rare genetic diseases affecting children at a high proportion, 30% of whom will not live to see their fifth birthday.

We understand (as noted in a recent *San Francisco Business Times* article) that CIRM currently is undergoing a re-prioritization process when it comes to funding.

**As California taxpayers, residents, patient caregivers and professionals, we wanted to take this opportunity to strongly urge CIRM to continue to allocate at least 50 percent of its funding to clinical research into rare diseases (figure pulled from CIRM's annual reports) based on the following facts: Rare diseases with high unmet need affect a large population of Californians – and regenerative medicine holds the keys to cures and therapies.**

One in ten Californians – approximately 3 million residents – are living with rare disorders. Many of these patients – half of them children – face fatal, life-threatening, and/or profoundly disabling disease outcomes, and the majority of them currently have no treatment. When you account for the approximately three additional family members impacted financially, emotionally, physically and mentally by each rare disease patient, rare diseases impact a total of 9 million Californians. Further, 80% of rare disorders are caused by specific genetic mutations which are most effectively addressed by the regenerative medical interventions CIRM is designed to fund. The expense of these patients to the State of California is 3 to 5 times higher than those of patients without rare diseases, and can be as high as \$200,000 a year per patient ([NIH study suggests people with rare diseases face significantly higher health care costs | National Institutes of Health \(NIH\)](#)). Continuing to fund rare disease research will ultimately save the lives of

Californians, and result in reduced healthcare costs statewide – this is a significant and measurable benefit to taxpayers.

### **1. CIRM bylaws specifically mandate research into orphan/rare diseases**

In Article 2, Section 1 of the CIRM bylaws: *(a) To make grants and loans for stem cell and genetic research, for research facilities, and for other vital research opportunities to realize therapies, protocols, and/or medical procedures that will result in, as speedily as possible, the cure for, and/or substantial mitigation of, major diseases, injuries, and orphan diseases.*

### **2. Funding rare disease research leads to a greater understanding of more common conditions and can yield medical breakthroughs for those diseases**

As stated in CIRM's 2023 Annual Report, *"Investigating rare diseases, defined as impacting fewer than 200,000 Americans, presents opportunities for impactful regenerative medicine treatments and breakthroughs. Exploring their interconnectedness maximizes the impact of CIRM funding and may improve healthcare outcomes for more people."* For example, the intersectionality of rare diseases and neurological diseases including Alzheimer's and Parkinson's is significant. Rare disease research will likely yield important findings to significantly impact the treatment of those more common diseases.

### **3. If CIRM de-prioritizes funding for rare disease research, millions of Californians with rare conditions will be left with no hope or treatments on the horizon**

CIRM has led the way – not only for Californians with rare diseases, but for global rare disease patients – by funding rare disease research, which is otherwise left largely unfunded due to the lack of investment by the pharmaceutical industry, investors and venture capital firms. Funding is readily available for larger indications. For example, the federal government is investing \$3.8 billion for Alzheimer's research, the therapeutics market for Alzheimer's is valued at \$4.24 billion and is expected to grow to \$15.10 billion by 2030. However, the majority of today's 10,000+ known rare diseases (the majority of these diseases with only 50-2,000+ patients diagnosed) cannot take advantage of the capital markets due to their populations currently being too small for pharma investor returns. Rare disease patient advocacy groups – many based in California – alone can't shoulder the burden of funding this research. Even if they could, this would result in

significant inequities as patient advocacy groups with the resources to drive treatments are usually led by families in high socio-economic categories.[1] Again, leaving millions of Californians with rare diseases effectively abandoned from a health perspective.

#### **4. CIRM funding is the missing link needed to fund cures and treatments for rare diseases**

Unlike other, more common diseases (e.g., Alzheimer's), we have the science and the technology today to create life-changing and often curative treatments for rare diseases. What is needed to close the gap between today's disease and tomorrow's treatment/cures is funding. In the past five years, gene-based technology development has burgeoned. The technology needed to address 80% of genetically defined rare diseases has been developed and is waiting for funding to deploy it. Two powerful recent examples — the application of gene therapy for SMA (Spinal Muscular Atrophy) patients and the current gene-based therapy clinical trials for Angelman Syndrome, Rett Syndrome and NGLY1 deficiency. In addition, California centers of excellence – UCLA, UCSD, UCSF, UC Davis, USC, Stanford, CalTech and other California universities – are focused on rare diseases and ready to put CIRM funding into action for treatments and cures. This will expedite results and return taxpayer dollars.

Rare diseases are a public health crisis and exactly where public, taxpayer dollars can and should make the biggest impact. CIRM has become a key partner for the development of rare disease therapies and has profound impact on the possibility of delivering lifesaving and life-changing therapies to patients with the highest unmet need and burden of disease. In finding cures and treatments for rare diseases, CIRM will ultimately save the lives of Californians, and reduce healthcare costs statewide – a significant and measurable benefit to taxpayers.

Again, as leaders of California-based patient advocacy organizations, researchers, clinicians and drug developers, and as California taxpayers, residents, patient caregivers and professionals, we strongly urge CIRM to continue to allocate at least 50 percent of its funding to clinical research into rare diseases.

Signed by: (See attached PDF of signatures)

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
1	Andrea	Kossler	Academia	Palo Alto	Stanford University				
2	Zara	Patel	Academia	Woodside	Stanford				
3	FRANK	MCCORMICK	Academia	San Francisco	UCSF				
4	Alysson	Muotri	Academia	San Diego	UC San Diego				
5	David	J. Segal	Academia	Davis	University of California, Davis				
6	Pete	Schmidy	Academia	Scotts Valley	Stanford University				
7	Sangeeta	Joshi	Academia	Fremont	Research				
8	Paul	HarmTz	Academia	San Francisco	University of California San Francisco				
9	Julian	Halmaj	Academia	Sacramento	UC Davis				
10	Jill	Silverman	Academia	Sacramento	UC Davis SOM				
11	Stephanie	Cherqui	Academia	San Diego	University of California San Diego				
12	Betty	Cabrera	Academia	Carlsbad, CA	University of California San Diego				
13	Rachel	Vassar	Academia	San Francisco	UCSF				
14	Dawn	Gano	Academia	San Francisco	UCSF				
15	Kenneth	Phung	Academia	Los Angeles	University of Southern California				
16	Akash	Virupakshiah	Academia	San Francisco	UCSF				
17	Donna	M Ferriero	Academia	San Francisco	UCSF				
18	David	Blair, MD PhD	Academia	San Francisco	University of California San Francisco				
19	Irene	Chang, MD, MSc	Academia	San Francisco	UCSF				
20	Gerry	Lipshutz	Academia	Los Angeles	UCLA				
21	Shafali	Jeste	Academia	Los Angeles	Children's Hospital Los Angeles				
22	Julia	W. Chang, PhD.	Academia	Los Angeles	UCLA David Geffen School of Medicine				
23	Emma	Rybalka	Academia	N/A	Rare disease researcher				
24	Jeanne	Paz	Academia	San Francisco	Gladstone Institute of Neurological Disease				
25	Isaac	Chang	Academia	San Francisco	Gladstone Institutes				
26	Catherine	Argyriou	Academia	Los Angeles	McGill University				
27	Deanna	Necula	Academia	San Francisco	UCSF				
28	Yuliya	Voskobiynek	Academia	San Francisco	Gladstone Institutes				
29	Annastasia	Bohn	Academia	Yuba City					
30	Remu	Navaz Gangji	Academia	San Francisco	Medical Genetics Resident Physician (UCSF)				
31	Heather	Santos	Academia	San Juan Capistrano	Daughter has 3 rare disorders				
32	Sonali	Bisoyi	Academia	Fremont					
33	Cecilia	Fairley	Academia	San Francisco	UCSF Genetic Counselor				
34	Amandeep	Salhotra	Academia	La Canada	Know patients affected with ADSSL1 myopathy				
35	Vivianna	DeNittis	Academia	San Francisco	Rare disorder researcher				
36	Ritu	Malhotra	Academia	Fremont	My neighbors daughter has the disease CDKL5.				
37	Jan	Noita	Academia	Sacramento	Professor, UC Davis- we work with several rare disease foundations and patients who rely on CIRM				
38	Emilie	Tu	Academia	Berkeley	Best friend has FOXP1 syndrome				
39	Adam	Numis	Academia	San Francisco	Clinician/Associate Professor				
40	Maija	Steenari	Academia	Orange	Child Neurologist/Epilepsy specialist				
41	Carla	Francisco	Academia	San Francisco	Physician taking care of these patients				
42	Pankaj	Chordia	Academia	Fremont	CDKL5				
43	Olivia	Kim-McManus	Academia	San Diego	Principal investigator/researcher for rare disease ASO trials				
44	Alex	Fay	Academia	Oakland	Physician (child neurologist)				
45	Allisandra	Rha	Academia	Orange, CA	Researcher				
46	Ana	Cortez	Academia	Temecula	My husband has epilepsy				
47	Henry	Lee	Academia	Boston	Boston Children's Hospital				
48	Stanley	Nelson	Academia	Los angeles	Ucla rare disease physician scientist				
49	Susan	Hiniker	Academia	Stanford	Physician				
50	Ann	Oh	Academia	San Francisco	UCSF				
51	Joseph	Gleeson	Academia	San Diego	I am a physician treating patients with rare disorders				
52	Brandon	Mahelona	Academia	Sacramento	Friends Daughter				
53	R	W	Academia	San Diego	friend of affected family				
54	Alison	Black	Academia	San Diego	Friend of rare disease family				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
55	Emmanuelle	Tiongson	Academia	Los Angeles	Physician - Academic institution				
56	Lynda	Polgreen	Academia	Torrance	The Lundquist Institute at Harbor-UCLA				
57	Donald	Kohn	Academia	Los Angeles	Investigator on gene therapy for rare diseases				
58	Agnes	Chen	Academia	Torrance	Neurologist				
59	Kathleen	Curtius	Academia	Escondido	UCSD Researcher and Mother to a child with a Rare Disease				
60	Cheryl	Cooper	Academia	Encinitas	Neighbor and SDA colleague				
61	Brian	Coveney	Academia	Los Angeles					
62	Chloe	Davis	Academia	San Diego					
63	Katherine	Reindl	Academia	San Diego	A friends son				
64	Rebecca	Miller	Academia	San Francisco	Friend				
65	Logan	Bender	Academia	Encinitas	My AP European History teacher has a son with Zimmerman Laband Syndrome				
66	Nicole	Bruce	Academia	San Diego	I'm a SLP and work with children with rare disorders				
67	Holly	Cook	Academia	Encinitas	My favorite high school teacher's son has a rare disease				
68	JT	Gruber	Academia	Encinitas	Student of Father				
69	Vivian	Blue	Academia	Encinitas	Personal connection				
70	Raymond	Wang	Academia	Orange	Physician for patients with Rare Disease				
71	Roger	Hollis	Academia	Los Angeles	Academic researcher				
72	Michelina	Iacovino	Academia	Torrance	The Lundquist Institute at Harbor-UCLA				
73	Reva	Frankel	Academia	San Francisco	Geneticist				
74	Chloe	Christensen	Academia	Fullerton	Rare Disease Researcher				
75	Jose	Abdenur	Academia	Orange	CHOC Children's Hospital				
76	Christopher	Luthers	Academia	Los Angeles					
77	Greta	Peng	Academia	San Francisco	Pediatric Neurologist				
78	Changrui	Xiao	Academia	Orange	Neurogeneticist				
79	Shih-hsin	Kan	Academia	Orange	Children's Hospital of Orange County				
80	Alexandra	Joelson	Academia	Carlsbad					
81	S	K	Academia	San Jose	Relative				
82	Sandra	Martinez	Academia	Del Mar	Special Ed Teacher				
83	Amanda	Sultan	Academia	Oakland					
84	Dakota	Burnett	Academia	Carlsbad	knows someone with disorder				
85	Bryn	Faris	Academia	San Diego	Friend				
86	John	Pompeo	Academia	San Diego	Friend				
87	charlotte	mignon	Academia	Los Angeles					
88	Charlie	Bland	Academia	Los Angeles					
89	Zoe	Mignon	Academia	Encinitas	none				
90	William	Lilley	Academia	Escondido	I work with nano rare patients				
91	Bhavya	Chhadva	Academia	San Jose					
92	Ravi	Shah	Academia	Milpitas	Family patient				
93	Aijun	Wang	Academia	Sacramento	UC Davis				
94	Roger	Morrisette	Academia	Valley center					
95	Yael	Weiss MD PhD	Industry	Moraga CA	Mahzi Therapeutics				
96	Farid	Vij	Industry	San Francisco, CA	CEO, Citizen Health				
97	Neil	Kumar	Industry	Palo Alto	BridgeBio				
98	Zhiyong	Tan	Industry	San Mateo	Citizen				
99	Charles	Homcy	Industry	San Francisco	BridgeBio, Third Rock Ventures				
100	Xing	Fang	Industry	San Mateo	Citizen Health				
101	Charles	Homcy	Industry	San Francisco	BridgeBio				
102	Adam	Shaywitz	Industry	Irvine	BridgeBio				
103	Nataliya	Agafonova	Industry	Los Angeles	Longeveron				
104	Huijuan	(Tracy) He	Industry	Fremont	QED				
105	Jovia	Nierenberg	Industry	Oakland, CA	BridgeBio Pharma				
106	Athiwat	Hutchaleelaha	Industry	San Francisco	BridgeBio Pharma				
107	Justin	To	Industry	Mountain View	BridgeBio				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
108	Mallory	Harden	Industry	San Francisco	BridgeBio				
109	Ehren	Werner	Industry	San Francisco	BridgeBio				
110	scott	collins	Industry	san francisco	bridgebio				
111	Sunil	Erraballi	Industry	Fremont	BridgeBio Pharma				
112	Jim	Byrd	Industry	Palo Alto	Rare Disease Advocate				
113	Butchi	Pinnamaraju	Industry	Pleasanton	Industry				
114	Christine	Zhang	Industry	San Francisco	Bridgebio				
115	Amelia	Gay Morton	Industry	San Mateo	Bridgebio				
116	Vinita	Dora	Industry	Los Angeles	Bridgebio				
117	Chinmay	Shukla	Industry	Santa Rosa	BridgeBio Pharma				
118	Amanda	Malakoff	Industry	San Francisco	BridgeBio				
119	Terry	Pirovolakis	Industry	Encino	Elpida Therapeutics SPC				
120	Tammy	McGraw	Industry	Antioch	BridgeBio				
121	Kahlil	D'Souza	Industry	San Francisco	Bridgebio Pharma				
122	Satish	Rao	Industry	San Francisco	BridgeBio Pharma				
123	Premal	Shah	Industry	Palo Alto	MyOme				
124	Jean-Francois	Tamby	Industry	San Francisco, CA	BridgeBio				
125	Jocelyn	Loo	Industry	San Francisco	Bridgebio				
126	Shannon	Nicole Levy	Industry	SAN FRANCISCO	Biotech worker				
127	Damian	Wilmot	Industry	Palo Alto	BridgeBio Pharma, Inc.				
128	Cybele	Gouverneur	Industry	San Francisco	BridgeBio				
129	Matt	Outten	Industry	Palo Alto	Biotech				
130	Julie	Hoegi	Industry	Belmont	BridgeBio pharma				
131	Mahesh	Mohnani	Industry	San Fransisco	Pharma industry				
132	Dani	Harmon	Industry	Palo Alto	BBIO				
133	TODD	BOBICK	Industry	DANVILLE	QED, BBGT, PORTAL				
134	Ananth	Sridhar	Industry	San Francisco	Industry				
135	Snow	Ge	Industry	San Francisco	QED Therapeutics				
136	Roberta	Pantani	Industry	Sane Francisco	BridgeBio				
137	Uma	Sinha	Industry	San Francisco	BridgeBio Pharma				
138	Michael	Bodulow	Industry	Petaluma, CA	Rare Disease BioTech Industry Employee				
139	Chris	Lorenz	Industry	Oakland	Mahzi Therapeutics				
140	Emily	Radomile	Industry	Corte Madera	Mahzi				
141	Josh	Loehrer	Industry	San Francisco	BridgeBio				
142	Ling-Ning	Santiago	Industry	Mountain View	QED				
143	Neel	"Bubba" Murarka	Industry	Portola Valley	BridgeBio				
144	sean	cullen	Industry	Los Gatos	Mahzi Therapeutics				
145	Maricel	Apuli	Industry	San Francisco	BridgeBio Pharma Inc.				
146	Micaela	Rodine	Industry	Sunnyvale	BridgeBio				
147	Jinesh	Jain	Industry	Cupertino	Abbott				
148	Danielle	Fries	Industry	Walnut Creek	Mahzi Therapeutics				
149	Jia	Ma	Industry	Palo Alto	Bridgebio				
150	Anna	Wade	Industry	Palo Alto	BridgeBio Pharma				
151	Shweta	Rane	Industry	San Francisco	BridgeBio Pharma, Inc.				
152	Erika	George	Industry	San Francisco	BridgeBio				
153	Yeshi	Mikyas	Industry	Thousand Oaks	Bridgebio				
154	Randall	Kaye	Industry	La Jolla	Longboard Pharma				
155	Mark	Hochstetler	Industry	Menlo Park	Codexis, Inc.				
156	Grace	Kim	Industry	San Francisco	BridgeBio				
157	Christina	Theodore-Oklota	Industry	San Francisco	Mahzi Therapeutics				
158	Dick	Meijer	Industry	Carlsbad	RareMD Inc				
159	Courtney	Grafe	Industry	San Francisco	BBIO				
160	Dhivya	Kumar	Industry	Palo Alto	BridgeBio				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
161	Temika	Talley	Industry	San Francisco	BridgeBio				
162	Cari	Zavattero	Industry	Santa Rosa, CA	Mahzi Thereapeutics				
163	Keilani	Finley	Industry	Walnut Creek	N/A				
164	Alfred	Ngaw	Industry	San Francisco	BridgeBio Pharma				
165	Leena	Prasad	Industry	Berkeley	Industry				
166	Yuhsin	Huang	Industry	Palo Alto	Bridgebio Pharma				
167	Olga	Vlaskina	Industry	San Francisco	Bridgebio				
168	Mandy	Yeung	Industry	San Francisco	BridgeBio				
169	David	Nader	Industry	South San Francisco	Alector				
170	Terralyn	Bickham	Industry	San Francisco	BridgeBio				
171	Joel	F. Cooper, PhD,	Industry	San Diego	Advaita Toxicology Group				
172	Warren	Merrifield, PhD	Industry	San Jose	NeuroDetect				
173	Carol	Zoltowski	Industry	San Francisco, Ca.	QED/ Bridge Bio				
174	Noelle	Germain	Industry	N/A	Quiver Bioscience				
175	Chris	Moxham	Industry	Palo Alto	Transcripta Bio				
176	David	Jacoby MD PhD	Industry	San Francisco	Rare disease development				
177	Sunita	Babbar	Industry	Palo Alto, San Francisco	pharmaceutical company working on rare diseases				
178	ROBIN	ANDERSON	Industry	San Jose, CA	BridgeBio				
179	Gjalt	Huisman	Industry	Redwood City	Embold Therapeutics				
180	Rex	Wiig	Industry	Anaheim	Celeris Systems, Inc				
181	Amanda	Schmieder	Industry	Novato	Industry				
182	Teja	Reddi	Industry	San Francisco	BridgeBio				
183	Andrea	Wilkinson	Industry	San Francisco	UCB				
184	Mandana	baradar	Industry	San Mateo	Program manager				
185	Steve	Schneider	Industry	San Francisco, CA	BridgeBio Pharma, Inc				
186	Olga	Botvinnik	Industry	San Francisco	Bridge Bio				
187	Austin	Moreau	Industry	Los Angeles	Unaffiliated				
188	Amelia	Mutere	Industry	Antioch	Ccc				
189	Shalu	Grover	Industry	Sunnyvale	Product Company				
190	Rajeev	Arora	Industry	India	None				
191	Thuy	Nguyen	Industry	Brisbane	Ultragenyx				
192	SriRekha	Banoor	Industry	Saratoga	Independent				
193	Reid	Kaplan	Industry	Los Angeles	Friend has son with rare disorder				
194	Laura	Streich	Industry	Calabasas	Friend				
195	Nianwei	Lin	Industry	San Diego	Company executive				
196	Victoria	Wong	Industry	San Francisco					
197	Pushpa	Shao	Industry	San Francisco	I work for BridgeBio a biotechnology compny focussed on development of treatments for rare diseases				
198	Gautam	Loonawat	Industry	san jose	friend's daughter CDKL5				
199	Vipin	Sharma	Industry	Fremont	Affected friends children				
200	Natasha	Serrano	Industry	Vista	Mom to a young child with rare sarcoma				
201	Amit	Sharma	Industry	Castro Valley					
202	Manikandan	Gangadharan	Industry	Fremont	Friend's Child is suffering from a rare disorder				
203	Kristin	Adkins	Industry	San Francisco	RN				
204	Reginald	Alex	Industry	San Diego					
205	Adora	Ndu	Industry	Palo Alto	BridgeBio Pharma				
206	Swaroop	Kalapur	Industry	San Jose CA	Aware of the situation and look forward to options for those affected.				
207	Rishi	Shukla	Industry	Fremont	CDKL5				
208	Roberta	Davis	Industry	Palo Alto					
209	Sanjay	Gupta	Industry	Los Gatos	Friend of patient				
210	Shalini	Sharp	Industry	San Francisco	Director, Mahzi Therapeutics				
211	Lisa	Kelly	Industry	Novato	All patients deserve access to potential treatments and cures, rare or not.				
212	Jigar	Parmar	Industry	Hayward					
213	Karan	Malhi	Industry	San ramon					

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
214	Chintan	Desai	Industry	Fremont, CA	Know someone who has this disorder CDKL5				
215	Ankit	Sawhney	Industry	Sunnyvale					
216	Sohil	Prajapati	Industry	California					
217	Akash	Bhargava	Industry	Los Altos					
218	Archana	Uppala	Industry	Saratoga	Friend's kids				
219	Rachael	Nomburg	Industry	Marina del rey					
220	Sara	Riordan	Industry	Roseville	My mom has a rare disease, and I'm a genetic counselor who works with many patients with rare disease.				
221	Atul	Singh	Industry	Fremont	Scientist				
222	Jennifer	Miller	Industry	SF	Ultragenyx				
223	Matt	Wilkinson	Industry	Napa	Through friends whose lives have been impacted.				
224	Scott	DeNobile	Industry	San Diego	My child had neuroblastoma at 14 months.				
225	Dhruvit	Thakkar	Industry	Santa Clara					
226	Jeff	Olson	Industry	Santa Clara	family				
227	Sarah	Enwright	Industry	San Diego	Clinical Research Consultant				
228	Vijay	Bendre	Industry	Fremont California	via team mate				
229	Daniela	Rogoff	Industry	Palo Alto	BridgeBio Pharma				
230	Kim	Cohee	Industry	Santa Rosa					
231	Marissa	Turner	Industry	Martinez	Family				
232	Anagha	Gupte	Industry	San Diego					
233	Samuel	Gordon	Industry	Carlsbad	A friend				
234	Radhika	Gunderman	Industry	Encinitas					
235	Paul	Debevec	Industry	Los Angeles	Friend of afflicted parent				
236	Kirsty	Mitchell	Industry	Encinitas					
237	Sharney	McLaughlin	Industry	Encinitas	Neighbor has rare disorder, spouse employed by company focused on drug discovery for rare diseases				
238	Dwight	Dollins	Industry	Pismo beach	A family member has been diagnosed				
239	Ryan	Shumate	Industry	Encinitas					
240	Bhavan	Mehta	Industry	Fremont	Family friend is going through this disorder				
241	Neelanshi	Varia	Industry	San Francisco					
242	Pallavi	Udmalpet rajan	Industry	San Francisco	Friends with the patients parents				
243	Nimish	Sule	Industry	San Francisco	Friend				
244	Amanda	Butler	Industry	California					
245	Kamalesh	Jain	Industry	San Ramon					
246	Morgan	Weberg	Industry	San Diego	Employee of an industry partner developing a novel ASM for Developmental and Epileptic Encephalopathies.				
247	Tommaso	Nesti	Industry	Mountain View	Via one of my colleague's experience				
248	Noah	Auerhahn	Industry	Oakland, CA	Parent				
249	Marvin	SooHoo	Industry	GLENDALE	Friend of adfected				
250	Madison	SooHoo	Industry	GLENDALE	Cousin of affected				
251	Timothy	Smith	Industry	San Diego	Director at a stem cell tool provider				
252	Nick	Mordwinkin	Industry	South San Francisco	Biotech executive				
253	Lawrence	Lee	Industry	San francisco					
254	Alena	Kopp	Industry	San Diego	Ally				
255	Viet	Nguyen	Industry	Anaheim	Biogen				
256	Claudia	Lee	Industry	San Mateo					
257	Jeffrey	Rubin	Industry	Berkeley	Senior Research Scientist at Regal Therapeutics				
258	Swati	Tole	Industry	Thousand Oaks	Biotech executive working on rare disease				
259	Luke	Bargabus	Industry	San Diego	Friend of family with a child suffering from rare disease				
260	Thuy	Nguyen	Industry	Garden Grove					
261	Julia	Pytte	Industry	La Jolla	Advocate and researcher				
262	Stacy	Bland	Industry	San Luis Obispo					
263	Anthony	Vu	Industry	San Diego	n-Lorem, scientist				
264	Melissa	Keenan	Industry	San Diego	Parent				
265	Emilie	Scherrer	Industry	San Francisco	Tempus				
266	Ria	Thomas	Industry	San Diego	n-Lorem Foundation				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
267	Donna	Butler	Industry	Oceanside	Worked in the industry				
268	Natalie	Abu Hamdan	Industry	San Diego					
269	Frank	Bennett	Industry	Carlsbad	Ionis Pharmaceuticals				
270	Gina	Wallar	Industry	Long Beach	Work				
271	Ethan	Perlstein	Industry	Oakland	Perlara				
272	Gautam	Jain	Industry	San Jose					
273	Shikha	Lodha	Industry	Milpitas					
274	Rajesh	Shetty	Industry	Fremont	Relative to patient				
275	A	S	Industry	mtv					
276	Virginia	Sankey	Industry	San Diego	Friends				
277	Monty	M	Industry	Fremont					
278	Wade T	Williford	Industry	San Diego	N-Lorem Foundation				
279	Aayush	Shah	Industry	Sunnyvale	A friend has it				
280	Archana	Jain	Industry	Cupertino	Friend				
281	Romil	Gandhi	Industry	Milpitas					
282	Rishab	Shah	Industry	San Diego	I know the family				
283	Kavya	Racharla	Industry	Santa Clara	Friend's children affected				
284	Monette	Cruz Pacheco	Industry	San Marcos					
285	Chiran	Jain	Industry	Fremont					
286	James	Green	Industry	Carlsbad					
287	Anita	Grandhi	Industry	Dublin	Family friends daughter has it				
288	David	Fisch	Industry	Palo Alto	Close family friends and work				
289	Elise	Brimble	Industry	San Francisco	Researcher and advocate				
290	Jainu	Jogani	Patient Advocacy group	San Francisco	CDKL5 Cure org				
291	Amanda	Eastmond	Patient Advocacy group	San Jose	Family Friend				
292	Annemarie	McHugh	Patient Advocacy group	Dublin	Fremont teacher				
293	Abby	Lievense	Patient Advocacy group	Los Angeles	CureSHANK				
294	Nasha	Fitter	Patient Advocacy group	Los Altos	Cofounder & CEO, FOXG1 Research Foundation				
295	Sunit	Mukherjee	Patient Advocacy group	Los Altos	None				
296	Bahar	Mojgani	Patient Advocacy group	San jose	TPMG				
297	Matt	Kossler	Patient Advocacy group	Menlo Park	Self				
298	Shruti	Jogani	Patient Advocacy group	Fremont	Parent				
299	Christine	Waggoner	Patient Advocacy group	Albany	Cure GM1 Foundation				
300	Min	Young	Patient Advocacy group	La Puente	Cure GM1				
301	Maisa	Fernandez	Patient Advocacy group	Los Altos	FoxG1				
302	Sanath	Kumar Ramesh	Patient Advocacy group	San Jose	<a href="http://curegpx4.org">curegpx4.org</a>				
303	Ami	Badani	Patient Advocacy group	Palo Alto	Self				
304	Martin	lee	Patient Advocacy group	San Francisco	Cdkl5				
305	Charu	Reddy	Patient Advocacy group	SAN JOSE	Cure GM1				
306	ilya	musayev	Patient Advocacy group	Fremont	Child's Cure Genetic Research				
307	Kimberly	Nye	Patient Advocacy group	Menlo Park, CA	TESS Research Foundation				
308	Mai	Porche	Patient Advocacy group	San Jose	Bridgebio				
309	Doug	Dooley	Patient Advocacy group	Albany, CA	Cure GM1 Foundation				
310	Amit	Jain	Patient Advocacy group	Cupertino	Family friend				
311	Shweta	Mehta	Patient Advocacy group	Campbell	Other				
312	Justin	West	Patient Advocacy group	Newport Beach	KCNT1 Epilepsy Foundation				
313	Liam	Cooney	Patient Advocacy group	Corte Madera	Uncle				
314	Sim	Gopalan	Patient Advocacy group	Milpitas	Rotary Club				
315	Geetha	Srinivasan	Patient Advocacy group	San Diego	None				
316	Bryce	Powerman	Patient Advocacy group	San Francisco	The DOCK8 Foundation				
317	Anuja	Nanavati	Patient Advocacy group	San Jose	Hope4Harper				
318	Lynsey	Chediak	Patient Advocacy group	Berkeley, CA	California Native & Rare Disease Patient				
319	Sunil	Ranka	Patient Advocacy group	Cupertino	Friends of Reyna				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
320	Zoe	Bailey	Patient Advocacy group	Fairfield	Syngap Research Fund				
321	Amber	Freed	Patient Advocacy group	Los Angeles	SLC6A1 Connect				
322	Alex	Hall	Patient Advocacy group	Murrieta	SynGAP Research Fund				
323	Kimberly	V. Feilen, Ph.D.	Patient Advocacy group	San Diego	Advocacy with EveryLife Foundation for Rare Diseases & Global Genes				
324	Monica	Harding	Patient Advocacy group	San Diego	Syngap Research Fund (SRF)				
325	Jessica	Bell	Patient Advocacy group	Bakersfield	Syngap Research Fund				
326	Erin	Leonard	Patient Advocacy group	Long Beach	Patient				
327	Revathi	srinivasan	Patient Advocacy group	Il	None				
328	Farah	Hall	Patient Advocacy group	Murrieta	SRF				
329	Fadi	Hanna	Patient Advocacy group	Murrieta	SRF				
330	michelle	magos	Patient Advocacy group	Campo ca	SRF				
331	Arvind	Jain	Patient Advocacy group	San Jose , ca	CDKL5				
332	Rajaa	Louka	Patient Advocacy group	San Diego	SRF				
333	Nancy	Stack	Patient Advocacy group	Irvine	President, Cystinosis Research Foundation				
334	Leena	Panwala	Patient Advocacy group	Fairfield, NJ	INADcure Foundation				
335	Fillip	Hanna	Patient Advocacy group	San Diego	SRF				
336	Jessica	Carlso	Patient Advocacy group	Arcata CA	Syngap Research Fund				
337	Ivan	Shallal	Patient Advocacy group	Wildomar	SRF				
338	Andrea	Knaak	Patient Advocacy group	Orange County'	Care Choice Hospice and Palliative Care				
339	Lauren	Lopez	Patient Advocacy group	Sacramento	Congenital Hyperinsulinism International				
340	Kevin	McEntee	Patient Advocacy group	Scotts Valley	SLC6A1 Connect				
341	Allyson	Weisse	Patient Advocacy group	Sacramento	Foundation for Angelman Syndrome Therapeutics				
342	Vanita	Jogani	Patient Advocacy group	San jose	Hope4harper				
343	Moore	Chung	Patient Advocacy group	Claremont	Parent				
344	Joshua	Call	Patient Advocacy group	Cathedral City	Ultragenyx				
345	Brandy	Dawson	Patient Advocacy group	Play Del Rey	Epilepsy Awareness				
346	Jessica	Rodríguez	Patient Advocacy group	Torrance	Mother				
347	Kathleen	Daigle	Patient Advocacy group	Torrance	Parent				
348	Alpesh	Jain	Patient Advocacy group	San Jose	Bay Area resident				
349	Cristina	Ramos	Patient Advocacy group	Pleasant Hill, CA	Epilepsy Awareness				
350	Lori	Tolan	Patient Advocacy group	Huntington Beach	Unverricht Lundborg Disease epilepsy				
351	Priyanka	Kakkar	Patient Advocacy group	Glendale	Patient advocate and mom of two affected children with rare disease ADSS1 Myopathy				
352	Kathleen	Kitts	Patient Advocacy group	San Diego	SynGap1 Research Fund				
353	Xiaowei	Jin	Patient Advocacy group	Boston	Chinese Organization for Rare Disorders				
354	Gabrielle	Rushing	Patient Advocacy group	San Francisco	CSNK2A1 FOUNDATION				
355	Rohan	Seth	Patient Advocacy group	Oakland, CA	Lydian Accelerator				
356	Ajay	Malhotra	Patient Advocacy group	Irvine	SLC6A1				
357	Paul	Harris	Patient Advocacy group	Cathedral City	Partner has epilepsy				
358	Hannah	Lowe	Patient Advocacy group	N/A	L-CMD Research Foundation				
359	Raisa	Aronova	Patient Advocacy group	Fremont	Child's Cure Genetic Research				
360	Sabrina	Merchant	Patient Advocacy group	Z	DLG4 Research Fund/Shine Syndrome Foundation				
361	Breanna	Cuevas	Patient Advocacy group	Bakersfield	Parent				
362	Deepika	Sharma	Patient Advocacy group	Glendale	Family Friends				
363	Tina	Midha	Patient Advocacy group	La Canada Flintridge	Parent of children with rare disease (Craniopharyngioma, Primary Ciliary Dyskinesia)				
364	Jon	Martin	Patient Advocacy group	Sacramento	Foxg1 Research Foundation				
365	Kris	Hutchins	Patient Advocacy group	San Diego, Ca.	Parent of a Child with Tuberous Sclerosis				
366	Saloni	Walia	Patient Advocacy group	Los Angeles	Rare disease advocate - friends kids have rare disease				
367	Victoria	Arreola	Patient Advocacy group	Lathrop	Advocate Caregiver				
368	Ashley	Hanna	Patient Advocacy group	Temecula	SRF				
369	Melissa	Rosina	Patient Advocacy group	Anaheim	Self				
370	Gustavo	Dziewczapolski	Patient Advocacy group	Palo Alto	A Foundation Building Strength (AFBS) for Nermaline Myopathy				
371	Michael	Jewell	Patient Advocacy group	Taft, CA	Grandfather				
372	Shania	Baweja	Patient Advocacy group	Glendale	rare disease				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
373	Swati	Chandra	Patient Advocacy group	Los Angeles	Rare Disease advocate				
374	Kedar	Nadkarni	Patient Advocacy group	South Pasadena	None				
375	Ryan	Phillips	Patient Advocacy group	Sacramento	FOXG1 Research Foundation CEO and Rare Disease Father				
376	Sarah	Martin	Patient Advocacy group	Sacramento	FoxG1 Research Foundation				
377	Lisa	Collea MD	Patient Advocacy group	Newport Beach	Mom of rare disease child				
378	Charlene	C Rodriguez	Patient Advocacy group	Lake View Terrace	myself				
379	Naveen	Baweja	Patient Advocacy group	Glendale	Rare Disease Parent				
380	Anita	Saxena	Patient Advocacy group	Valencia	Rare Disease Advocate				
381	Sandeep	Jain	Patient Advocacy group	Saratoga, CA	CDKL5				
382	Michaelle	Jinnette	Patient Advocacy group	Encinitas	Rare parent; patient-advocacy org founder and president				
383	M	Singhania	Patient Advocacy group	Irvine	Rare Disease Advocate				
384	Aaron	Harding	Patient Advocacy group	San Diego	SynGAP Research Fund				
385	Vivek	Shrivastava	Patient Advocacy group	Valencia	Rare Disease Advocate				
386	ash	d	Patient Advocacy group	Burbank	Rare disease advocate				
387	Sonal	Sehgal	Patient Advocacy group	Fremont	Kids of friends have rare condition				
388	Jasmine	Corona	Patient Advocacy group	Sylmar	<a href="http://Pmts.org">Pmts.org</a>				
389	Denise	Mitomi	Patient Advocacy group	Redondo Beach	CURESHANK				
390	Arvind	Maheshwari	Patient Advocacy group	Winnetka	Advocacy organization				
391	Nayan	Jain	Patient Advocacy group	Milpitas	CDKL5				
392	Pavan	Alapati	Patient Advocacy group	Los Angeles	None				
393	Annie	Jacquelin	Patient Advocacy group	Los Angeles	Abby Lievenese				
394	Dana	Glassburn	Patient Advocacy group	Los Angeles	CureShank				
395	Antonio	Diaz Bueno	Patient Advocacy group	San Diego	CureSHANK				
396	Renu	Dhillon	Patient Advocacy group	Fremont	rare disease advocate - CDKL5				
397	Jenny	Hontz	Patient Advocacy group	Westchester	None				
398	Jeliline	Vautier	Patient Advocacy group	Sacramento	Syngap Research Find/parent				
399	Elizabeth	Horner	Patient Advocacy group	Brentwood	Na				
400	Carrie	Hoffman	Patient Advocacy group	Los Angeles	Cure/SHANK				
401	Jennifer	Straiton	Patient Advocacy group	Santa Monica	LGS/genetics				
402	Silpa	Menon	Patient Advocacy group	Valencia	Rare disease advocate				
403	Janet	Prakash	Patient Advocacy group	Valencia	california				
404	Pankaj	Saxena	Patient Advocacy group	Santa Clarita	CDKL5				
405	Harsh	Mota	Patient Advocacy group	Fremont	CDKL5				
406	Sunny	Dugar	Patient Advocacy group	Fremont	Friend CDKL5				
407	Nirmal	Singh	Patient Advocacy group	Los Angeles	Family friend				
408	Julie	Sims	Patient Advocacy group	San Pedro	Family member has rare genetic disorder, PMS				
409	Meenal	Behl	Patient Advocacy group	Fremont					
410	Sribathravardhini	Kanagarajan	Patient Advocacy group	Fremont CA	Friends daughter				
411	Sarah	Chung	Patient Advocacy group	Culver City	Rare Disease Advocate				
412	Seung	Choy	Patient Advocacy group	Culver City	Rare Disease Advocate				
413	Melanie	Flood	Patient Advocacy group	Granite Bay	Mellie J Foundation				
414	Rashmi	Agrawal	Patient Advocacy group	Porter Ranch					
415	Vipul	Parmar	Patient Advocacy group	San Jose	My Friends daughter suffers from a rare disorder - CDKL5				
416	Raja	Gummadi	Patient Advocacy group	Los Angeles	Rare Decease Advocate				
417	Smita	Raizada	Patient Advocacy group	Santa Clarita					
418	Sandeep	Kumar	Patient Advocacy group	California	Rare disease advocate				
419	Priya.	C	Patient Advocacy group	Pleasanton	Rare disease advocate				
420	Fernanda	Lucio	Patient Advocacy group	Sacramento	CURESHANK				
421	Filipe	Lucio	Patient Advocacy group	Sacramento	CURESHANK				
422	Diogo	Lucio	Patient Advocacy group	Sacramento	CURESHANK				
423	David	Lucio	Patient Advocacy group	Sacramento	CURESHANK				
424	Olivia	Montano-Tritz	Patient Advocacy group	San Diego	PROS Foundation, C.U.R.E. Group (Undiagnosed Support Group)				
425	Judy	Cheng	Patient Advocacy group	Los Angeles	I have several friends whose children have rare disorders.				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
426	Vibha	Sekhri	Patient Advocacy group	San Jose	I'm not				
427	Janvi	Bambhania	Patient Advocacy group	Los Angeles	Rare disease advocate				
428	Poonam	Agrawal	Patient Advocacy group	Santa clarita	Rare disease				
429	Sravanthi		Patient Advocacy group	Pleasanton	Rare disease advocate				
430	Bipin	Nepani	Patient Advocacy group	Fremont	Impacted directly with close relatives				
431	Sou	Ach	Patient Advocacy group	Los Angeles					
432	Nirmal	Jain	Patient Advocacy group	Los Angeles	CDKL5				
433	Danielle	Lagas	Patient Advocacy group	Murrieta	CurrShank/Patient Advocacy Group				
434	Yiwei	She	Patient Advocacy group	Sacramento	TNPO2 Foundation				
435	Gay	Grossman	Patient Advocacy group	San Diego	Mother and Patient Advocate				
436	Swathi	Balakrishna	Patient Advocacy group	Stevenson Ranch	Rare disease advocate				
437	Wendi	Hauser	Patient Advocacy group	Los Angeles	Ally				
438	Lucy	Trevisani	Patient Advocacy group	Los Angeles	Friend has a rare genetic disorder.				
439	POOJA	RAUTELA	Patient Advocacy group	Fremont					
440	Mandvi	Sharma	Patient Advocacy group	Los Angeles	Rare Disease Advocacy				
441	Rajesh	Khandelwal	Patient Advocacy group	Northridge	Through my friend				
442	Lisa	Louda	Patient Advocacy group	San Ramon	Phelan McDermid mom				
443	Marissa	Krupat	Patient Advocacy group	Culver City					
444	Raman	Walia	Patient Advocacy group	Los Angeles	Rare disease advocate (Friend's children have rare disease)				
445	Michelle	Dollins	Patient Advocacy group	San Luis Obispo	Mother of a child with FOXC1				
446	Casey	Robertshaw	Patient Advocacy group	San Luis Obispo	Father of a child with FOXC1				
447	Stephanie	Johnston	Patient Advocacy group	Fort mcmurray	Our son has Phelan Mcdermid				
448	Summer	kellner	Patient Advocacy group	San jose	My son has LGS and drsvet syndrome				
449	Chelsea	Kidwell	Patient Advocacy group	Paso Robles, CA	My cousin's 1 year old daughter has FoxG1				
450	Chandra	Baliga	Patient Advocacy group	San Francisco	Rare Disease Advocate- Secretary and Director, Cure ADSSL1				
451	Desirae	Shepard	Patient Advocacy group	Inglewood	Friends son				
452	Darcy	Hughes	Patient Advocacy group	Los Angeles	Friend				
453	Lizeth	Juarez	Patient Advocacy group	Los Angeles	My self and my daughter have epilepsy				
454	Nitika	Saini	Patient Advocacy group	Hayward	rare disease advocate				
455	Parag	Samdadiya	Patient Advocacy group	Cupertino	Family friend				
456	Deepak	Mehta	Patient Advocacy group	San Jose	My niece is diagnosed with CDKL5				
457	Vishal	Bendre	Patient Advocacy group	Fremont					
458	Lisett	Castellanos	Patient Advocacy group	Bellflower	My son has Phelan McDermid syndrome				
459	Lucy	Derby	Patient Advocacy group	Los Angeles					
460	Yangyang	Xie	Patient Advocacy group	Riverside					
461	Saravanaselvan	Senguttuvan	Patient Advocacy group	Fremont					
462	Shivani	Soni	Patient Advocacy group	La Canada Flintridge	Research Scientist and Family Friend				
463	Aaditi	Palavalasa	Patient Advocacy group	San Jose					
464	Rashmi	Sinha	Patient Advocacy group	Mountain View	Have a child with a rare disease and founded a rare disease foundation				
465	Seema	Quadras	Patient Advocacy group	Valencia	Rare disease advocate				
466	Sneha	Pilgaonkar	Patient Advocacy group	Fremont	Know a friend				
467	Rajan	Kulkarni	Patient Advocacy group	Fremont	Know a friend				
468	Jayesh	Jain	Patient Advocacy group	San Francisco					
469	Jayesh	Jain	Patient Advocacy group	San Francisco					
470	Audrey	Vernick	Patient Advocacy group	San Francisco	parent and patient advocate				
471	Kay	Johnson	Patient Advocacy group	Sacramento	CDLK5				
472	Andres	Padilla III	Patient Advocacy group	Corona	I am a parent of a rare disorder child with FOXC1 Syndrome				
473	Charlene Son	Rigby	Patient Advocacy group	San Francisco	STXBP1 Disorders				
474	Mitul	Trivedi	Patient Advocacy group	Fremont					
475	Prachin	Ranavat	Patient Advocacy group	Pleasanton	CDKL5				
476	Jennifer	Glick	Patient Advocacy group	Tracy	My family is affected.				
477	Anna	Quint	Patient Advocacy group	San Diego	Close friends				
478	Jill	HAWKINS	Patient Advocacy group	N/A	FAM177A1 Research Fund				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
479	Lori	Henton	Patient Advocacy group	Oceanside	Parent				
480	Pua	Macario	Patient Advocacy group	San Diego	my daughter				
481	Manuel	Hernandez	Patient Advocacy group	San Diego	My 3-year-old daughter has a rare disease, DLG4 synaptopathy				
482	Norna	Lorenzana	Patient Advocacy group	San Diego	My 3-year-old granddaughter has a rare disease, DLG4 synaptopathy				
483	Mike	Graglia	Patient Advocacy group	Mill Valley	SynGAP Research Fund				
484	Linda	Payne	Patient Advocacy group	Santa Rosa	My daughter				
485	Swati	Nair	Patient Advocacy group	Los Angeles	CDKL5				
486	Allison	Scherer	Patient Advocacy group	Los Angeles	Friend				
487	Cathy	Reppert	Patient Advocacy group	Ontario Canada	CureShank				
488	Alejandra	Medel	Patient Advocacy group	Los angeles	My daughter has cdkl5 it's a rare genetic disorder that causes epilepsy and hard to control				
489	Fadwa	Hanna	Patient Advocacy group	Murrieta	SRF				
490	Faris	Hanna	Patient Advocacy group	Murrieta	SRF				
491	Joann	Nau	Patient Advocacy group	Anaheim	Foxg1				
492	Linda	Bird	Patient Advocacy group	Buena park	Foxg1				
493	anurag	phadke	Patient Advocacy group	sun					
494	Danny	Miller	Patient Advocacy group	Corte Madera	My two sons have MEPAN Syndrome, an ultra rare mitochondrial disease. I established a foundation in 2019 to discover treatments to improve their quality of life.				
495	Sitara	Purushotham	Patient Advocacy group	Los Angeles	Rare disease advocate				
496	Vishwajit	Pantvaidya	Patient Advocacy group	San Jose	Friends relative had CDL5				
497	Maralou	Higgins	Patient Advocacy group	Exeter	patient				
498	Heidi	Bjornson-Pennell	Patient Advocacy group	San Francisco	Parent of 2 children with primary ciliary dyskinesia; Lead of the Rare As One Network				
499	Mia	Marano	Patient Advocacy group	Los Angeles	Friend's child, my own child				
500	Kathleen	Robertshaw	Patient Advocacy group	ATASCADERO	grandparent				
501	Sarva	Channarajurs	Patient Advocacy group	San Jose	Friend of a parent who has a kid with rare disease				
502	Grace	Li	Patient Advocacy group	Mountain View, CA	CureSHANK				
503	Joanna	Kent	Patient Advocacy group	San Jose	Parent of a child				
504	Tatiana	Martinez	Patient Advocacy group	Foresthill	Child has PMS				
505	Jason	Piccioni	Patient Advocacy group	Agoura Hills	Friend				
506	Tanya	Wahlquist	Patient Advocacy group	Santa Barbara	CureShank				
507	Sarah	Fulop	Patient Advocacy group	Escondido	I have Vascular EDS a rare disease				
508	Mary	Landsfield	Patient Advocacy group	Rancho Palos Verdes	Phelan-McDermid Syndrome				
509	Leticia	Groom	Patient Advocacy group	Fullerton	Patient caregiver				
510	Sanjana	Baliga	Patient Advocacy group	San Carlos	Family friend				
511	Evelyn	Lee	Patient Advocacy group	La Crescenta	Family member				
512	Andreas	Borg	Patient Advocacy group	SF	Father CDKL5				
513	Jeanette	Weisman	Patient Advocacy group	Alameda	Parent to a child with a rare disease				
514	Audrey	Vernick	Patient Advocacy group	San Francisco	Patient advocate				
515	Sandra	Asher	Patient Advocacy group	San Jose	Ally				
516	David	Stodolny	Patient Advocacy group	Burbank	CureShank				
517	Nikola	Leibold	Patient Advocacy group	Winchester	Phelan McDermid syndrome child				
518	Philipp	Rockel	Patient Advocacy group	San Francisco	Friend's daughter				
519	Ben	Fraser	Patient Advocacy group	Cardiff					
520	Eileen	Zimmerman	Patient Advocacy group	Encinitas	Parkinsons, Fragile X, Angelman's, and more.				
521	Rebecca	Duncan	Patient Advocacy group	Encinitas	Friend				
522	Landon	Block	Patient Advocacy group	Encinitas					
523	Molly	Vonder	Patient Advocacy group	San Diego	family friend				
524	Tiffany	Murphy	Patient Advocacy group	Encinitas	Family Friend				
525	Stacey	Levine	Patient Advocacy group	Encinitas	Friend of the family				
526	Jenny	Hong	Patient Advocacy group	Encinitas	I know someone's child with rare disorder.				
527	Michael	Di Sano	Patient Advocacy group	Newport Beach, CA	KCNH1				
528	Kassandra	Pas	Patient Advocacy group	Sacramento	Friends' child				
529	Sheldon	Pas	Patient Advocacy group	Sacramento	Friends' child				
530	Alvaro	De Murguia	Patient Advocacy group	San Diego	Patient advocate				
531	Jennifer	Maziek	Patient Advocacy group	Encinitas	Cure KCNH1 Foundation				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
532	Julia	Straka	Patient Advocacy group	Encinitas	Cure KCNH1				
533	Seth	Levine	Patient Advocacy group	Encinitas	Friend of someone with child with KCNH1				
534	Sean	Head	Patient Advocacy group	San Jose	Friends Son has one				
535	Jenna	Nienhuis	Patient Advocacy group	Encinitas					
536	Katie	Shelton	Patient Advocacy group	Auburn	My son had the disorder				
537	Ashlyn	Gray	Patient Advocacy group	Carlsbad	Friend				
538	Laura	Bennett	Patient Advocacy group	Oceanside	friend and coworker who has a child with a rare disorder				
539	Gai	Ayalon	Patient Advocacy group	Moraga	Chief Drug Development Officer, FOXG1 Research Foundation				
540	Reanne	Finwall	Patient Advocacy group	Sacramento	FoxG1 niece				
541	Kelly	Hawkins	Patient Advocacy group	San Marcos					
542	DUSTIN	HAWKINS	Patient Advocacy group	SAN MARCOS	Friend of disorder patient				
543	John	Cannon	Patient Advocacy group	Burbank	Interested				
544	Yanbing	Hong	Patient Advocacy group	Palo Alto	Parent				
545	Robert	Gobbo	Patient Advocacy group	ENCINITAS					
546	Karen	Arguijo	Patient Advocacy group	Encinitas	Cure KCNH1 Foundation supporter				
547	Chris	Straka	Patient Advocacy group	Encinitas					
548	Julaina	Calero	Patient Advocacy group	Palmdale	My daughter has Phelan McDermid Syndrome				
549	Karen	Telleen-Lawton	Patient Advocacy group	SANTA BARBARA	friend of family, son has a different rare disease				
550	kristian	keeneey	Patient Advocacy group	rancho santa fe					
551	Anne	Mueller	Patient Advocacy group	Walnut Creek	family friend				
552	Sarah	Nichter	Patient Advocacy group	San Diego	Rare disease org, friend of patient with rare disease				
553	Annika	Maxwell	Patient Advocacy group	San Diego	Treatments for Tristan donator				
554	Alicea	Engquist	Patient Advocacy group	Castro Valley, CA					
555	Karen	Chebatoris	Patient Advocacy group	Los Angeles	Neighbor of person with rare disorder				
556	Don	Quarford	Patient Advocacy group	Encinitas	Friend				
557	Julie	Kraft	Patient Advocacy group	Pleasanton	Loved one				
558	Max	Vennemeyer	Patient Advocacy group	Carlsbad	Friend of Parent of Child with disorder				
559	Zachary	Burns	Patient Advocacy group	Dublin	Father of Myhre syndrome patient; member of Myhre Syndrome Foundation				
560	Sally	Hogan	Patient Advocacy group	Rancho Cucamonga					
561	Jaydin	Dean	Patient Advocacy group	San Diego					
562	Sherry	Grandaw	Patient Advocacy group	La	Dear friend son has it				
563	Elizabeth	Hergesheimer	Patient Advocacy group	Encinitas	Friend of family				
564	Lynn	Bellomi	Patient Advocacy group	Arroyo Grande	parent				
565	Dushanka	Klacar	Patient Advocacy group	Encinitas	Friends with a rare disease family				
566	Samaan	Mahmoudzadeh	Patient Advocacy group	Anaheim	Close friend				
567	Desiree	Marr	Patient Advocacy group	Encinitas	Know a child with it.				
568	Steven	Willing	Patient Advocacy group	Encinitas	Concerned citizen				
569	Isabel	Guzman	Patient Advocacy group	Woodland	CDKL5				
570	Jessica	Gove	Patient Advocacy group	ENCINITAS	Friends				
571	Jonathan	Gove	Patient Advocacy group	Encinitas	Friends				
572	Isabella	Villamizar	Patient Advocacy group	Carlsbad	I know someone who's family member has a rare disorder.				
573	Ethan	Farrell	Patient Advocacy group	Encinitas	My Teachers child				
574	Maya	Federico	Patient Advocacy group	Encinitas	Teacher				
575	Joseph	Janni	Patient Advocacy group	Encinitas	My teacher.				
576	Lauryn	Camareno	Patient Advocacy group	Encinitas	Teacher				
577	Jen	Rexroad	Patient Advocacy group	Granite bay	My daughter has kcnh1				
578	Grace	Keefe	Patient Advocacy group	Carlsbad	my friend's kid has KCNH1				
579	Sebastian	Corn	Patient Advocacy group	San Diego	A teacher of mines child has a rare disorder				
580	mary	pruitt	Patient Advocacy group	carlsbad	family				
581	Emily	Mancini	Patient Advocacy group	Fresno					
582	Beatrice	Lundell	Patient Advocacy group	San Diego					
583	Alia	Lewis	Patient Advocacy group	Carlsbad	Teacher's family				
584	Kajal	Sozan	Patient Advocacy group	Sacramento	CDKL5				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
585	Naweed	Sozan	Patient Advocacy group	Natomas	CDKL5				
586	Ella	Hinkle	Patient Advocacy group	Encinitas	Teacher's son				
587	Saurabh	Chopra	Patient Advocacy group	Fremont					
588	Jane	Weaver	Patient Advocacy group	Santa Barbara	Friend of someone with the disorder				
589	Carol	Slaton	Patient Advocacy group	Santa Ana	Friend with son who has a rare disease				
590	Carolyn	Galipault	Patient Advocacy group	Encinitas					
591	Angela	Vazquez-Herrera	Patient Advocacy group	San Diego	A colleague's child has a rare disease. A friend's mother and a friend's brother.				
592	Arianna	Trette	Patient Advocacy group	Encinitas	Supporter				
593	Rachel	Kanevsky	Patient Advocacy group	Los Angeles	Friend of someone with a rare disease				
594	Megan	Levan	Patient Advocacy group	Encinitas					
595	Christine	Dennis	Patient Advocacy group	Carlsbad					
596	Alex	Vennemeyer	Patient Advocacy group	Encinitas					
597	Gwyneth	Huber	Patient Advocacy group	Encinitas	Teacher's son has rare disorder.				
598	Cassandra	Cinzori	Patient Advocacy group	Encinitas	Supporter of Tristan				
599	Ava	Keochekian	Patient Advocacy group	Encinitas					
600	Bryn	McCarren	Patient Advocacy group	Encinias	student of Kevin Witt				
601	Monica	Witt	Patient Advocacy group	Newport's Beach	My grandson has a deletion on the KCNH1 gene				
602	Donald	Bargabus	Patient Advocacy group	Encinitas, CA	A friend has this disorder				
603	Jill	Carter	Patient Advocacy group	Encinitas					
604	Sanaea	Cowasjee	Patient Advocacy group	Encinitas					
605	Sonja	Ross	Patient Advocacy group	Nebraska	Hnrmpu				
606	Natalie	Dolce	Patient Advocacy group	Sacramento	Friend				
607	Holly	Balardeta	Patient Advocacy group	Encinitas	Friends				
608	Ranelle	Mathews	Patient Advocacy group	Encinitas					
609	Sarah	Humes	Patient Advocacy group	San Diego	Friends and family				
610	Eve	Alosio	Patient Advocacy group	San Diego	Friend				
611	Steve	Alosio	Patient Advocacy group	Oceanside	Friend				
612	Julie	Rowland	Patient Advocacy group	Loomis	Friend				
613	Christopher	Gallegos	Patient Advocacy group	San Diego	Friend's child has it				
614	Autumn	Kleinrath	Patient Advocacy group	Encinitas					
615	Isabella	Espinosa	Patient Advocacy group	San Diego	My mom works with people with Parkinson's and my teacher's son has a rare disease that needs treatment.				
616	Kyle	Simon	Patient Advocacy group	encinitas	Friend of Michaelle				
617	Lurlyn	Reyes	Patient Advocacy group	Palo Alto	Bridgebio				
618	Dave	MacLeod	Patient Advocacy group	Lake Forest	Friend				
619	Ana	Gomez	Patient Advocacy group	Cardiff					
620	Julia	Cornacchione	Patient Advocacy group	San Diego	Know someone with a rare disorder.				
621	Patti	Brockman	Patient Advocacy group	Pacific Palisades	Friend				
622	Jennifer	Rexroad	Patient Advocacy group	Woodland	Aunt				
623	Elisa	Suarez-Barrett	Patient Advocacy group	Encinitas	Family friends of Tristan a 4 year old who has been suffering from KCNH1 and depends on every possible funding in order to fight for a healthy life				
624	Zell	Williams	Patient Advocacy group	Encinitas	A friend's son has a rare disease				
625	Rachel	Miller	Patient Advocacy group	Carlsbad					
626	Melissa	Whitenight	Patient Advocacy group	Menlo Park	Aunt of two with SLC13A5				
627	Katherine	Huang	Patient Advocacy group	Carlsbad	Treatments for Tristan				
628	Katherine	Von Berg	Patient Advocacy group	San Marcos	Friend with KCNH1 Family				
629	Paul	Fitzpatrick	Patient Advocacy group	Oakland	Ally				
630	Nimish	Baweja	Patient Advocacy group	Glendale	Patient				
631	Kasey	Nye	Patient Advocacy group	Menlo Park	Family member				
632	Darius	Shayegan	Patient Advocacy group	Encinitas	Friends and colleagues affected				
633	Mala	Chaudhari	Patient Advocacy group	Milpitas	Close friend				
634	Bhavya	Nagda	Patient Advocacy group	Fremont	Close relationships				
635	Eliese	Holt	Patient Advocacy group	Carlsbad	Friend's child				
636	Anne	Engert	Patient Advocacy group	Oceanside, ca	Friend				
637	Earl	Bailey	Patient Advocacy group	Fairfield	Parent of a child with a rare disorder				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
638	Manoj	Punamia	Patient Advocacy group	Pleasanton					
639	Sabrina	Castillote	Patient Advocacy group	WA	Rare Disease parent & NW Rare Coalition				
640	Audrey	Tyler	Patient Advocacy group	Encinitas	Supporter of Cure KCNH1 Foundation				
641	Zalak	Shah	Patient Advocacy group	Fremont					
642	Nitin	Chatlani	Patient Advocacy group	Carlsbad	Supporting from afar <3				
643	Dhara	Bavishi	Patient Advocacy group	San Jose	Na				
644	Brad	Rexroad	Patient Advocacy group	Granite Bay	Parent of a child afflicted				
645	Dhyanesh	Bagadia	Patient Advocacy group	Milpitas	Friends and family.				
646	Prachin	Ranavat	Patient Advocacy group	Pleasanton	Patient				
647	Dev	Shah	Patient Advocacy group	Mountain View ca	Good Samaritan				
648	Rahul	Parekh	Patient Advocacy group	Newark					
649	Dipti	Gandhi	Patient Advocacy group	San Jose					
650	Deven	Shah	Patient Advocacy group	Fremont	None				
651	Colin	Bonnicksen	Patient Advocacy group	Atascadero	My Nephew				
652	Alexis	Hoerres	Patient Advocacy group	San Diego	Friend of someone with rare disorder				
653	Samuel	Wiles	Patient Advocacy group	San Diego	Friend of someone with rare disorder				
654	Rujul	Shah	Patient Advocacy group	Milpitas					
655	Victoria	Polanco Ramirez	Patient Advocacy group	Stockton, Ca.	Two of my siblings are diagnosed with a rare disorder- Syngap1				
656	Amanda	Giffillen	Patient Advocacy group	San Diego	My friend's son has KCNH1				
657	Joanna	Ashline	Patient Advocacy group	North Tustin - Orange Cour	Parent of child with Syngap1				
658	Julie	Walters	Patient Advocacy group	Novato	Parent of a child with a RD and Board Member of PCDH19 Alliance				
659	Jinesh	Gandhi	Patient Advocacy group	Milpitas	My friend is impacted				
660	Rushabh	Sanghvi	Patient Advocacy group	Milpitas	Friend of parent who's child is suffering from it				
661	Heta	Shah	Patient Advocacy group	Fremont					
662	Scott	Mestemaker	Patient Advocacy group	Newtown	Son has Syngap1				
663	Anna	Vennemeyer	Patient Advocacy group	Carlsbad	My teacher's son				
664	Megha	Shah	Patient Advocacy group	Fremont	Through a friend				
665	Jinesh	Doshi	Patient Advocacy group	Fremont, CA	Type 1 diabetes				
666	Shobna	Sharma	Patient Advocacy group	Fremont	Friend				
667	Bushra	Coban	Patient Advocacy group	Carlsbad					
668	Arti	Bhandari	Patient Advocacy group	Dublin	Family friends child				
669	Jayesh	Ahah	Patient Advocacy group	Milpitas	Friend				
670	Marie	Casciano	Patient Advocacy group	Canyon country					
671	Kruti	Shah	Patient Advocacy group	Sunnyvale	None				
672	Kym	Masterson	Patient Advocacy group	Encinitas					
673	Joe	Mandelbaum	Patient Advocacy group	Manhattan Beach	My granddaughter has been diagnosed with CDKL5				
674	Leslie	Cinzori	Patient Advocacy group	Encinitas	Supporting a friend and supporting the community of those with rare genetic disorders.				
675	Erik	Knuppel	Patient Advocacy group	San Francisco	Friend				
676	Mandeep	Raj	Patient Advocacy group	San Jose	One of my friends is affected by it				
677	Aparna	Jain	Patient Advocacy group	San jose	Auto immune disorders relative				
678	Andrea	Compton	Patient Advocacy group	New york	My son has DRPLA				
679	Adam	Araneo	Patient Advocacy group	Eureka	Friends child				
680	Sheila	Higgins	Patient Advocacy group	Hillsborough	Family friend				
681	Lu	Wang	Patient Advocacy group	Los Altos	okur-Chung neurodevelopmental syndrome				
682	Pat	Buttress	Patient Advocacy group	Orange. CA	I am a friend of Dr. Justin West and his family. Andrew deserves a chance that only your continued funding can provide.				
683	Philip	Wente	Patient Advocacy group	Livermore	Friend of family of CSNK2A1 child				
684	Ted	Cocoles	Patient Advocacy group	Aptos	Friends suffer from rare disorder				
685	Sophie	Druskin	Patient Advocacy group	Hillsborough	family friend				
686	Thomas	Wagner	Patient Advocacy group	San Mateo	Dad of a child with Alexander Disease -- a California Prof is researching a treatment giving the community hope.				
687	Jay	Martin	Patient Advocacy group	Citrus Heights	Grandparents				
688	Rick	Dunaj	Patient Advocacy group	Westlake Village	Parent of patient				
689	William	Marr	Patient Advocacy group	Atherton	Friend's daughter				
690	Suzanne	Lightstone	Patient Advocacy group	Los Angeles					

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
691	Karl	Hernandez	Patient Advocacy group	Montrose	Contributor				
692	Simone	Press	Patient Advocacy group	Los Angeles	Child is a victim				
693	Mark	Doyle	Patient Advocacy group	Newport	Lawyer				
694	Nisha	Trivedi	Patient Advocacy group	South San Francisco	I'm a rare disease patient				
695	Monica Joanna	Einekaveh	Patient Advocacy group	Los Angeles	Mother of Eleanor Cure GABA-A				
696	Piret	Saagpakk	Patient Advocacy group	San Francisco	My child is affected by SMC1A DEE				
697	Sarah	Ghavim	Patient Advocacy group	View Park	CSNK2A1 Foundation				
698	Sripal	Jain	Patient Advocacy group	Dublin ca	Family friend				
699	Amy	Richardson	Patient Advocacy group	Burlingame	CSNK2A1 Foundation				
700	Gay	Grossman	Patient Advocacy group	La Jolla, California	Parent Advocate				
701	Steve	Grossman	Patient Advocacy group	La Jolla	Rare parent, cofounder of research and advocacy organization.				
702	Amanda	Bergen	Patient Advocacy group	Santa Clarita	Mom of daughter with Pheian-McDermid syndrome				
703	Martin	SooHoo	Patient Advocacy group	GLENDALE	Friends of affected				
704	McKenzie	SooHoo	Patient Advocacy group	GLENDALE	Cousin of affected				
705	Michael	Foy	Patient Advocacy group	Los Angeles	Father of son who has disorder				
706	Vaishali	Bhosale	Patient Advocacy group	La Cañada Flintridge	Friend				
707	Megan	Peitzke	Patient Advocacy group	Venice	Friends				
708	Nitin	Chawla	Patient Advocacy group	La Canada	Friends and Family				
709	helen	Gates	Patient Advocacy group	Danville	Family				
710	Beiyong	Zhang	Patient Advocacy group	San Francisco					
711	Annie	Schly	Patient Advocacy group	Mar Vista	Friends son has the disorder				
712	Steve	Druskin	Patient Advocacy group	Hillsborough	Friend				
713	Geri	Landman	Patient Advocacy group	Berkeley	Parent of a child with a rare disease, director of a rare disease advocacy group				
714	Jocelyn	Duff	Patient Advocacy group	Ipswich, MA ---I run a rare	Mom/Caregiver/Exec Director of CureCMT4J--research-based rare disease NPO dedicated to expediting a treatment/cure for my child and others with her disorder				
715	Spela	Mirosevic	Patient Advocacy group	Palo Alto	Mother of a child with a rare disease - CTNNB1 Syndrome				
716	Shelley	Scifres	Patient Advocacy group	Newport Beach	Friend				
717	Lindsay	Okamoto	Patient Advocacy group	San Mateo, CA	Work for a PAG rare disease organization				
718	Johanna	Smith	Patient Advocacy group	San Mateo					
719	Laajvanthi	Mahendra	Patient Advocacy group	Sunnyvale					
720	Charlene Son	Rigby	Patient Advocacy group	San Francisco	STXBP1				
721	Nicole	Ambrose	Patient Advocacy group	San Diego	SMC1A Foundation, mother of a child with a rare disorder (SMC1A DEE/CdLS)				
722	Melissa	Hioco	Patient Advocacy group	Roseville	STXBP1 Encephalopathy				
723	Jason	Hioco	Patient Advocacy group	Roseville	STXBP1 Encephalopathy				
724	Jamie	Kim	Patient Advocacy group	Fremont	STXBP1 Foundation				
725	Martina	Moody	Patient Advocacy group	Hawthorne	Parent of Patient				
726	Russ	Novy	Patient Advocacy group	Danville	parent				
727	Robert	Sandusky	Patient Advocacy group	Huntington Beach	Support				
728	Catherine	Mackin	Patient Advocacy group	San diego	My cousin has a rare disorder				
729	Sheila	Witt	Patient Advocacy group	Tustin, CA					
730	Elizabeth	Meadows	Patient Advocacy group	Mission Vally	Parent of a child with SMC1A-DEE				
731	Monica	Witt	Patient Advocacy group	Newport's Beach	Grandparent				
732	Lauren	Willner	Patient Advocacy group	San Diego	Parent of child with a rare disease				
733	Isabela	Martinez	Patient Advocacy group	Encinitas					
734	Leslie	DuVall	Patient Advocacy group	Irvine	Friend				
735	Vijayanti	Reddy	Patient Advocacy group	Los Angeles					
736	Joann	Kreps	Patient Advocacy group	Encinitas	Friends of a rare disease family				
737	Lauren	Gonzales	Patient Advocacy group	Encinitas	My high school teacher's child has a rare disease				
738	Dana	Strano Daitch	Patient Advocacy group	Encinitas	Friends of a family				
739	Dawn	Mayeda	Patient Advocacy group	Encinitas	Neighbors				
740	Caitlin	Chapman	Patient Advocacy group	San Diego					
741	Darla	Lovrin	Patient Advocacy group	Moraga	supporter				
742	Ranjana	Sankhala	Patient Advocacy group	Saratoga	Rheumatoid Arthritis and Sjogren's Syndrome				
743	Arundathi	Kadiyala	Patient Advocacy group	Orlando					

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
744	rashmi	maheshwari	Patient Advocacy group	San Jose	My friend's both kids aged 18 & 16 are dependent on this study				
745	Erika	Pike	Patient Advocacy group	Encinitas	Friend if someone who has it				
746	Jennifer	Hanson	Patient Advocacy group	Encinitas	Community supporter				
747	Carol	Hennebelle	Patient Advocacy group	Oeange	Friend				
748	Grace	Scholl	Patient Advocacy group	Encinitas					
749	Amit	Jain	Patient Advocacy group	Cupertino	My daughter has rare disorder				
750	Tatiana	Garachtchenko	Patient Advocacy group	Brentwood, Cintra Costa c	Mother of a child with rare disorder				
751	Sahil	Shah	Patient Advocacy group	Newark	Relative				
752	Parth	Savla	Patient Advocacy group	Fremont, CA	A dear friend has a baby who is suffering from this disorder				
753	Mithal	Kothari	Patient Advocacy group	San Jose	I know someone indirectly suffering from this disorder.				
754	Niket	Bhodia	Patient Advocacy group	Aliso Viejo	I know individuals with rare disorders and they daily struggles these individuals and their caretakers face.				
755	Kavita	Mahendra	Patient Advocacy group	Bay area	Via a friend				
756	Siddhartha	Donthula	Patient Advocacy group	San Diego					
757	Subramaniam	Kandaswamy	Patient Advocacy group	Fremont	One of my friend's daughter has it.				
758	Nitin	Jain	Patient Advocacy group	Cupertino	Family				
759	Chand	Mehta	Patient Advocacy group	Santa Clara	A good friend had a family member with rate disorder.				
760	Kelly	Cobb	Patient Advocacy group	San Ramon	Child				
761	Paras	Doshi	Patient Advocacy group	San Jose					
762	Amitabh	Dixit	Patient Advocacy group	Pleasanton	Have seen this disease impact in the friends and family circle				
763	Marisa	Kuntz	Patient Advocacy group	San Marcos	Friend				
764	Nisha	Sharma	Patient Advocacy group	Alameda					
765	Syma	Dar	Patient Advocacy group	Torrance	Parent				
766	Parveen	Sancheti	Patient Advocacy group	Sunnyvale	Through a Very close friend				
767	Allen	Chin	Patient Advocacy group	Los Angeles	Parent				
768	Laurie	Waddell	Patient Advocacy group	Westchester	Friend, Cureshank				
769	Shradha	Bagrecha	Patient Advocacy group	Sanjose					
770	Abhishake	Jakn	Patient Advocacy group	Sanjose					
771	Lata	Sankla	Patient Advocacy group	Sanjose					
772	Parag	Sankla	Patient Advocacy group	Sanjose					
773	Kushal	Sankla	Patient Advocacy group	Sanjose					
774	Oliver	Roll	Patient Advocacy group	Los Altos					
775	Anna	Fitter	Patient Advocacy group	Laguna niguel	Family				
776	Jaden	Fitter	Patient Advocacy group	Laguna Niguel	My cousin				
777	Zubin	Fitter	Patient Advocacy group	Laguna niguel	Family				
778	Kevin	Witt	Patient Advocacy group	Encinitas	Cure KCNH1 Foundation				
779	Rebecca	Siskin	Patient Advocacy group	Long Beach	Cousin				
780	Kamran	Sadr	Other	San Jose, CA	The Permanente Medical Group				
781	Quoc	Mai	Other	Stanton, CA	None				
782	Yasmin	Garcia	Other	Ridgecrest	Parent				
783	Elaine	Ackerman	Other	N/A	BridgeBio				
784	Karthika	Raghuraman	Other	Milpitas	N/A				
785	Nathalie	picard	Other	San Francisco	None				
786	Surendra	Mehta	Other	Fremont	Grand Father				
787	Courtney	Schmitt	Other	Oakdale	Rare Disease Parent				
788	Michele	Williams	Other	Orange County	RN/ Parent of young adult with Dravet Syndrome with SCN1A mutation				
789	Kathryn	Davidson	Other	Novato	None - individual				
790	David	A. Weinstein, MD	Other	Albany, CA	Cure GM1 Scientific Advisory Board				
791	Monica	Hanover	Other	Menlo Park	California taxpayer				
792	Latika	Pokharna	Other	Castro Valley	Friend				
793	Ritika	Vashisht	Other	Fremont	Friend				
794	Polina	Feldman	Other	Mountain View	Chan Zuckerberg Initiative Foundation				
795	Aman	Jain	Other	Dublin	CDKL5				
796	Jeff	Sarnat	Other	San Francisco	N/A				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
797	Vijay	Krishnan	Other	Dublin, CA	Parent				
798	Rosa	Bogarin/ Mother	Other	Hanford	Donte McDonald/ Son				
799	Gene	Evans	Other	Menifee	Epilepsy				
800	Aswin	Jain	Other	Fremont	Community				
801	Kathryn	Morris	Other	Los Angeles	Mother and advocate				
802	Carrie	Williams	Other	Newport Beach	Kitchen Table Marketing				
803	Manish	Kothari	Other	san jose	CDKL5				
804	Marla	Rosenblum	Other	Simi Valley	Parent				
805	Nicole	Vincent	Other	Ramona	Epilepsy caregiver				
806	Melissa	Brizee	Other	Woodland Hills	Parent				
807	Shamim	Haldankar	Other	Redwood City	Speech language pathologist				
808	Tara	Sparks	Other	Bakersfield	Parent and Spouse of Rare patients				
809	Marie	Beckstaiger	Other	Rancho Murieta	Family				
810	Zachary	Landman	Other	Lafayette, CA	Sutter East Bay Medical Group				
811	Katie	Diecker	Other	Woodlan Hills	none				
812	Lydia	coathup	Other	Kingwood, Texas	Mom of special need teen daughter and friend of two families living with PMS				
813	Ashok	Volati	Other	Los Angeles	Independent				
814	Dilip	Bhandari	Other	Fremont CA	CDKL5				
815	Chirag	David	Other	Los Angeles	Individual CDKL5				
816	Pam	Chapin	Other	San Francisco, greater Bay	Teacher of children with rare disorders				
817	Jennifer	ocampo	Other	Claremont	Foxg1				
818	Moore	chung	Other	Claremont	FOXG1				
819	Deniz	Ustun	Other	Los Angeles	Friend's son				
820	Mahendra	Kumar	Other	Cupertino	CDKL5				
821	Vijay	Sharma	Other	Santa Clarita	Supporter of this cause				
822	Bhavin	Lakhani	Other	San jose	Know patients suffering from such disorder.				
823	Rakesh	Jain	Other	Oxnard	friend's daughter CDKL5				
824	Giriraj	Jain	Other	Cupertino	CDKL5				
825	Deepthi		Other	Los Angeles	Have a kid with fragile x syndrome				
826	Raman	bindlish	Other	San Francisco					
827	Chandraprakash	Loonker	Other	Los Angeles	Friend's daughter CDKL5				
828	Stacey	Packard	Other	Sacramento	Granddaughter had Dravet				
829	Suresh	Narasimhan	Other	Fremont, CA	friends affected				
830	Julie	R	Other	Poway	Friend, Parent Support				
831	Melissa	schmidt	Other	San diego	Launchbio				
832	Uday	Vashisht	Other	Fremont	Friend				
833	Aathavan	Thayabaran	Other	Newark	Know a friend who has one of those				
834	Deepali	Arya	Other	San Francisco	Through friends				
835	Mary	Cooney	Other	Corte Madera, CA	Aunt of a person with a rare disease				
836	Chaitanya	Chinthireddy	Other	Fremont	Friend				
837	Surabhi	Dwivedi	Other	Fremont					
838	Marquis	Harrell	Other	Philadelphia PA	My Daughter has Fox G1 syndrome				
839	Rahul	Pandey	Other	Cupertino	Scientist				
840	POOJA	RAUTELA	Other	Fremont					
841	Leanne	Vujnovich	Other	Costa Mesa, CA	I find it valuable research for rare diseases as well as the additional findings for other diseases.				
842	Diana	Belio	Other	San Diego	My 3-year-old daughter has a rare disease, DLG4 synaptopathy				
843	Anita	Jain	Other	Santa clarita	CDKL5				
844	Parush	Garg	Other	San Jose					
845	Simone	Sullivan	Other	San Diego	Epilepsy foundation				
846	Salil	Choudhry	Other	Irvine	In friends family				
847	Cheyenne	Camp	Other	San Diego	Friends & family. Rare disease job.				
848	Sheryl	Radomile	Other	Tiburon	grandmother				
849	David	Akers	Other	Millbrae	Friend of affected family				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
850	Jan	West	Other	Corona Del Mar	Grandmother of KCNT1 child				
851	William	Pai	Other	Alameda, CA					
852	Tina	Hernandez	Other	Campbell	Parent of a child with a rare disease				
853	Erin	Arthur	Other	Cameron Park	Parent				
854	Tina	Jones	Other	Redding Ca	Son has rare disorder				
855	Gloria	Wong	Other	San Jose	Friend				
856	Kevin	Wittig	Other	Montebello	Family Friend				
857	Angie	Calkins	Other	La habra	Patients mother				
858	Thomas	Mathai	Other	Elk Grove	Parent				
859	Amy	Williford	Other	San Diego	Employed by a non-profit working on therapies for rare disorders				
860	Karla	Gutierrez	Other	Corona	Parent to a child with a rare disorder				
861	Roberto	Gutierrez	Other	Corona	Parent to a child with a rare disorder				
862	Martha	Gutierrez	Other	Corona	Grandparent to a child with a rare disorder				
863	Roberto C	Gutierrez	Other	Corona	Grandparent to a child with a rare disorder				
864	Erick	Gutierrez	Other	Corona	Uncle to a child with a rare disorder				
865	Ernestina	Ornelas	Other	Anaheim	Grandparent to a child with a rare disorder				
866	Stephanie	Arias Ochoa	Other	Corona	Caregiver to a child with a rare disorder				
867	Michele	Mashburn	Other	San Jose	Know parents of children and others with rare disorders.				
868	Carlos	Gutierrez	Other	Foothill Ranch, Ca	My son is epileptic				
869	Teresa	Mastreani	Other	San Rafael	parent of individual with Phelan-McDermid syndrome				
870	John	Carbone	Other	San Diego	Donation to Tristan				
871	Julie	Garn	Other	Corona del Mar	Family Friend's child				
872	Danielle	Fredricks	Other	Carlsbad	Friend / Caretaker				
873	Piper	Smith	Other	Cardiff	Supporter				
874	John	Perkins	Other	San Diego	Concerned parent				
875	Jessie	Wick	Other	San Diego	Advocate				
876	Daniel	Leek	Other	Sacramento	Friends daughter has foxg1				
877	Sandra	Williams	Other	Temecula	Friend of Friend				
878	Zavien	Fisher	Other	Fair Oaks	Friends with children with rare disorder				
879	Betty	McDonald	Other	Del Mar	Friend of family with child with rare disorder				
880	Beth	Shelby	Other	Los Angeles, CA	Acquaintance				
881	Elizabeth	Fissori	Other	Arroyo Grande					
882	May	Liu	Other	Encinitas	A friend's child has KCNH1				
883	Bianca	Marquez	Other	Palm desert ca	My son				
884	Kelly	Porterfield	Other	Los Angeles	Personal Friend				
885	Blaine	McCafferty	Other	San Diego	Supporter of families with children battling rare disease				
886	Katherine	Arguijo-Flaiz	Other	Encinitas	KCNH1				
887	Tom	Villanueva	Other	Encinitas	neighbor				
888	Tracy	Olguin	Other	Corona	Parent of child with epilepsy				
889	Meghan	Lenehan	Other	Encinitas	Friend of Michaelle Jinnette who's son, Tristan, has a rare disorder				
890	Denise	Brent	Other	Huntington Beach, CA	Cure KCNH1 Foundation supporter				
891	Theresa	Martinez	Other	Encinitas					
892	Caitlin	Nichols	Other	San Francisco, CA	Former research team member, rare disease research startup				
893	Nina	Binetti	Other	San Francisco	Former employee of rare disease therapeutic companies; ally and friend				
894	Alice	von Simson	Other	Encinitas	A family we know is affected but also every child and every family matters and deserves a chance!				
895	Emily	Shane	Other	San Diego	My teacher's son				
896	Ganon	Notley	Other	San Diego	Know someone with one				
897	Katherine	Richards	Other	Carlsbad	Big supporter of Tristan and his family and support finding the cure for KCNH1!				
898	Angela	Georgens	Other	Encinitas					
899	Bruce	Windoffer	Other	San Diego	Friend of several patint families				
900	Marianne	Shamlou	Other	Encinitas	Friend				
901	Mariette	Hughes	Other	Carlsbad	Friend of someone with rare disorder				
902	Claudia	Cencelli	Other	San diego	Friend				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
903	Noor Jahan	Hussain	Other	San Diego	My friend's son has a rare disorder				
904	Renee	Labar	Other	Encinitas					
905	Nicole	Arce	Other	Apple Valley	Parent				
906	Erica	Delorme	Other	Encinitas	Supporter				
907	Sarah	LaVake	Other	Del Mar	Former student of a teacher who has a child with a rare disorder				
908	Lori	Neale	Other	Encinitas	Personal				
909	Kerry	Hermann	Other	Chico ca	Friends have a rare disease				
910	Teresa	Faber	Other	San Marcos	I'm a Speech Language Pathologist who works with children with rare disorders.				
911	Zoe	Meredith	Other	Los Angeles	Friend				
912	Mark	Lawrence	Other	San Marcos					
913	Amelie	Pasco	Other	Encinitas					
914	Aimee	Brazeau	Other	Pasadena	Family member has been diagnosed with a rare disease				
915	Catrina	Stanley	Other	Encinitas	Neighbor				
916	Melissa	McNeal	Other	Pismo Beach	I have epilepsy and i work in social education.				
917	Ella	Decking	Other	San Diego	One of my teachers sons has a rare disease				
918	Matt	Rexroad	Other	Woodland	Niece				
919	Amber	Turley	Other	Lafayette	Parent				
920	Christian	Zao	Other	San Diego	Supporter for research				
921	Paras	Shah	Other	Sunnyvale	Self				
922	Rinku	Ranka	Other	Cupertino					
923	Olivia	Bell	Other	Carlsbad	I know someone with it				
924	Jini	Porwal	Other	Fremont					
925	Colleen	Bonnicksen	Other	Atascadero	My nephew has a rare disorder.				
926	Zach	Bary	Other	Encinitas	A student of Mr. Witt, who's son was diagnosed with a rare disease				
927	Linda	Rios	Other	San Jose	Friend				
928	Kanan	Sheth	Other	San Jose	Daughter of a close friend				
929	Becky	Kasinger	Other	Orange, CA	Supporter				
930	Pratibha	Udmalpet	Other	San Francisco					
931	Julianna	Fike	Other	Sacramento					
932	Mandar	Chitnis	Other	Torrance	Got to know from a friend				
933	Sweta	Jogani	Other	Newark					
934	Vibha	Vora	Other	Los Altos	Close family member has Tourette syndrome				
935	Yanhong	Shi	Other	Duarte, CA	Researcher working on rare disorders				
936	Lisa	Kellerman	Other	Sunnyvale	I have one				
937	Mihir	Shah	Other	Fremont					
938	Bhargav	Maniyar	Other	San Jose					
939	Ruchi	Maniyar	Other	San Jose					
940	Christina	Gonzalez	Other	Modesto	I was born chronically ill due to a rare complication that I experienced in the womb. Now, I live with multiple rare disorders				
941	M	Radcliff	Other	Sacramento					
942	Emily	Hsu	Other	San Carlos	Friends with the parents/caregivers of kids with rare disorders				
943	Amy	Silver	Other	Alamo					
944	Sujatha	Kalyanam	Other	Campbell					
945	Padmavati	Tatapudy	Other	San Jose	I do my dear friends child having one and the costs are exorbitant, let alone the trouble & pressure of handling the child.				
946	Spurthi	Yenreddy	Other	Campbell					
947	Shah,	Taral	Other	San Jose					
948	Elizabeth	Hirsch	Other	San Francisco	Friends, and friends with children with rare diseases				
949	Michael	Alper	Other	Nipomo					
950	Roz	Keller	Other	Eureka					
951	Denise	Grossman	Other	Woodland Hills	Supporter				
952	Evanna	Dunlop	Other	Daly City	Spouse of Parkinson's Disease Patient				
953	Sakunthala	Sundarrajan	Other	Hayward	Parent and also work in the industry				
954	Rachel	Adams	Other	Santa monica	A friend of someone who's son has a rare disease				
955	Rick	Dahlseid	Other	San Diego	Concerned Father				

	First Name	Last Name	Type of organization	Location (city in CA)	Affiliation (how are you associated to rare disorder)				
956	Meenakshi	Vohra	Other	Cupertino	my friend's kids are diagnosed with this				
957	Maria	Gamez Zielke	Other	Lake Forest	Through a family member being diagnosed with one				
958	Sharyn	Goodson	Other	San Diego	Friend				
959	Todd	Miller	Other	CAMARILLO	friend				
960	James	Stephens	Other	Dublin					
961	Jerica	Lenberg	Other	San Diego	Genetics clinician				
962	Sonja	Tappan	Other	San Mateo California	Friend of rare disorder families				
963	Faith	Edrosolano	Other	Redondo Beach	My engineering senior project involved manufacturing a tool to help a child with a rare disease (KCNH1)				
964	Lee	Toomey	Other	El Dorado Hillsa	Concerned citizen				
965	Marc	Peterson	Other	Modesto	My 8 year old son has Primary Ciliary Dyskinesia (aka PCD)				
966	Schuyler	Mann	Other	Torrance	Donor				
967	Ankit	Shah	Other	Tracy					
968	Gloria	Derosa	Other	Port orchard, wa	Daughter with Pitt-Hopkins				
969	Sneha	Jain	Other	Pleasanton					
970	Kylie	White	Other	Carlsbad	Friend of a child who has it				
971	Laurence	Mignon	Other	Encinitas	nLorem Foundation				
972	Forum	Shah	Other	Bay area	Friends				
973	Niveditha	Tammewar	Other	La Cañada	Friend				
974	Sirisha	P	Other	Chino					
975	Mythili	Seeni	Other	Los angeles	Friend				
976	Janaki	Ravinutala	Other	Mission Viejo					
977	Patricia	Leming	Other	Bonita	I have had students with rare diseases				
978	Siva	Natarajan	Other	La Canada Flintridge	Friends are impacted				
979	Leslie	Taylor	Other	San Diego	n-Lorem Foundation				
980	Katherine	Smith	Other	Oceanside	n-Lorem Foundation				
981	NADER	ABU HAMDAN	Other	San Diego					
982	Helen	Pu	Other	San Diego	n-Lorem Foundation				
983	nafiso	hussein	Other	san diego					
984	Annabelle	Steiner	Other	San Diego					
985	Alexia	Cordova	Other	San Diego					
986	Kimberly	Butler	Other	Escondido, CA	n-Lorem Foundation				
987	Michelle	Hariman	Other	San Diego					
988	Sanya	Jain	Other	Santa Clara					
989	Avani	Vora	Other	Fremont					
990	Daniel	Sankey	Other	San Diego	Friends				
991	Maureen	Finkelstein	Other	Solana Beach	Friends				
992	Savita	Devareddy	Other	Simi Valley					
993	Shaun	Butler	Other	Escondido	Family				
994	Suvarna	Lodha	Other	Saratoga					
995	Lanie	Quintana	Other	Roseville	I am working at BridgeBio.				
996	Denise	Gang	Other	Ponte vedra fla	My grandson				
997	Kaushal	Shah	Other	Fremont	Acquaintance's child suffering rare disorder				
998	Madhavi	Gande	Other	Fremont					
999	Elizabeth	Linek	Other	Carlsbad	Relative				
1000	Richard	Ottaviano	Other	Berkeley	grandfather				
1001	Yasmin	Ahmad	Other	San Diego	Friend has a rare disease				
1002	Saroj	Punamia	Other	Pleasanton					
1003	JugrajSripal	Jain	Other	Dublin, CA					
1004	Viragi	shah	Other	Milpitas					
1005	Pari	Holliday	Other	Laguna Niguel	My niece				