

Year	Therapeutic Area	Name of Beneficiary Institution	Program/Project Description	Support Type	Country	Currency	Individual Payment Amount	Approved
2019	Thalassemia	Thalassemia International Federation (TIF)	Financial support for TIF Plan of Activities for 2019: - THAL-E Educational platform - Capacity building workshops for Patient Associations - Development of TIF facts sheets and infographics library for patients - Creation of TIF's young Patient Advisory Panel	Financial Support	Cyprus	EUR	€ 101,000.00	Yes
2019	Rare Diseases	EveryLife Foundation	EveryLife Foundation 2019 Activities: - Newborn screening Bootcamp - Rare on the road educational meetings for patients and caregivers at a local level	Financial Support	United States	USD	\$ 25,000.00	Yes
2019	ALD	International Patient Organisation for Primary Immunodeficiencies (IPOPI)	Sponsorship of 2019 EU Rare Disease Newborn Screening Campaign Program	Financial Support	United Kingdom	EUR	€ 15,000.00	Yes
2019	ALD	The Calliope Joy Foundation	Sponsorship of Cupcake Gala fundraising to support leukodystrophy patients in the US and abroad	Financial Support	United States	USD	\$ 2,500.00	Yes
2019	Thalassemia	Cooley's Anemia Foundation (CAF)	Sponsorship of CAF Care Walk for Thalassemia Day 2019	Financial Support	United States	USD	\$ 15,000.00	Yes
2019	Thalassemia	Cooley's Anemia Foundation (CAF) California Chapter	Sponsorship of the 4th Annual World Thalassemia Day Celebration 2019	Financial Support	United States	USD	\$ 650.00	Yes
2019	Thalassemia	Cooley's Anemia Foundation (CAF)	Sponsorship for the 2019 CAF Gala	Financial Support	United States	USD	\$ 11,000.00	Yes
2019	Rare Diseases	Organization for Rare Diseases India	Racefor7 a 7Km walk run or crawl to raise awareness about 7000 rare diseases between USA and India	Financial Support	United States	USD	\$ 1,000.00	Yes
2019	ALD	Fight ALD	Sponsorship to raise awareness of ALD among NBS stakeholders and reactive request to support NBS families in California with bluebird bio unbranded materials	Financial Support	United States	USD	\$ 14,000.00	Yes
2019	Sickle Cell	Association DrepaGrefe	Grant to support DrepaGrefe's Plan of Activities for 2019: Registry brochure, 2019 annual meeting, festivities for International Sickle Cell Disease Day and production of new testimonial videos	Financial Support	France	EUR	€ 5,000.00	Yes
2019	Sickle Cell	Cayenne Wellness Center and Children's Foundation	Sponsorship for the 11th Annual Sickle Cell Disease Educational Seminar	Financial Support	United States	USD	\$ 6,000.00	Yes
2019	Multiple Myeloma	Blood & Marrow Transplant Information Network	Sponsorship of a Second Chance at Life Survivorship Symposium	Financial Support	United States	USD	\$ 5,000.00	Yes
2019	Sickle Cell	Sickle Cell Community Consortium (SCCC)	Sponsorship for the 2019 SCCC Leadership Summit	Financial Support	United States	USD	\$ 25,000.00	Yes
2019	Sickle Cell	Greater Boston Sickle Cell Disease Association	Sponsorship for the 2019 Red Ribbon Gala and Scholarship Awards for the Greater Boston Sickle Cell Disease Association	Financial Support	United States	USD	\$ 10,650.00	Yes
2019	Sickle Cell	Sickle Cell Foundation of Minnesota	Sponsorship for the 2019 Management of Sickle Cell Disease Symposium	Financial Support	United States	USD	\$ 1,500.00	Yes
2019	Sickle Cell	Sick Cells	Support for the Sick Cells 2019 Education and Advocacy Campaign - Faces of Sickle Cell Storytelling Initiative	Financial Support	United States	USD	\$ 25,000.00	Yes
2019	Sickle Cell	Sickle Cell 101	Support for Sickle Cell 101 2019 Projects and Programs: Social media education & campaign, The Sickle Cell podcast and SC101 International.	Financial Support	United States	USD	\$ 21,319.00	Yes
2019	Sickle Cell	Martin Center Sickle Cell Initiative	Sponsorship of the 2019 Indiana Sickle Cell Conference	Financial Support	United States	USD	\$ 1,000.00	Yes
2019	Sickle Cell	Sickle Cell Disease Association of America (SCDAA)	Sponsorship of SCDAA's 2019 Sickle Cell Advocacy Day	Financial Support	United States	USD	\$ 10,000.00	Yes
2019	ALD	Fundacion Lautaro Te Necesita	Sponsorship of the 6th Annual Meeting of Families with Leukodystrophies	Financial Support	Argentina	USD	\$ 10,000.00	Yes
2019	ALD	United Leukodystrophy Foundation (ULF)	Sponsorship of the 2019 ULF Scientific Symposium and Family Conference	Financial Support	United States	USD	\$ 15,000.00	Yes
2019	Sickle Cell	Sickle Cell Association of Texas Marc Thomas Foundation	Sponsorship of the 2019 Sickle Cell Empowerment Conference and Cell-A-Bration Camps to provide transportation, assistance and educational supplies.	Financial Support	United States	USD	\$ 4,800.00	Yes
2019	Sickle Cell	The Next Step Fund	Next Step "Night Out" Fundraising Benefit to support teens and young adults living with chronic life-threatening illnesses	Financial Support	United States	USD	\$ 2,500.00	Yes
2019	ALD	Child Neurology Foundation	2019 Corporate Membership - Corporate Advisory Board	Financial Support	United States	USD	\$ 25,000.00	Yes
2019	ALD	United Onlus	Support of UNITED's 2019 programs: ☑ Leadership trainings ☑ Website development ☑ Newsletter support ☑ Patient empowerment events	Financial Support	Italy	EUR	€ 15,000.00	Yes

27	2019	Rare Diseases	Genetic Alliance UK	Support for Genetic Alliance UK 2019 patient engagement workshop	Financial Support	United Kingdom	GBP	£	8,500.00	Yes
28	2019	ALD	Associazione Italiana Adrenoleucodistrofi (AIALD)	Sponsorship of AIALD Onlus education material development	Financial Support	Italy	EUR	€	7,000.00	Yes
29	2019	Thalassemia	DEGETHA	Support for DEGETHA mental health education sessions	Financial Support	Germany	EUR	€	15,000.00	Yes
30	2019	Sickle Cell	Maryland Sickle Cell Disease Association (MSCDA)	Support of MSCDA's 2nd Annual Sickle Cell Patient, Family and Provider Symposium	Financial Support	United States	USD	\$	2,500.00	Yes
31	2019	Sickle Cell	SOS Globi Federation	Support of SOS Globi 2019 education materials including: • Website Development • Fundraising and Awareness	Financial Support	France	EUR	€	15,000.00	Yes
32	2019	Multiple Myeloma	International Myeloma Foundation	Sponsorship of 10th International Myeloma Working Group (IMWG) Summit	Financial Support	United States	USD	\$	25,000.00	Yes
33	2019	Multiple Myeloma	International Myeloma Foundation	Support of The 20th Support Group Leader (SGL) Summit	Financial Support	United States	USD	\$	25,000.00	Yes
34	2019	Rare Diseases	EURORDIS	2019 Corporate Membership -ERTC Round Table of Companies	Financial Support	France	EUR	€	10,000.00	Yes
35	2019	Rare Diseases	National Organization for Rare Disorders (NORD)	2019 Corporate Membership - PA for Education Workshop Group	Financial Support	United States	USD	\$	10,000.00	Yes
36	2019	Rare Diseases	National Organization for Rare Disorders (NORD)	Sponsorship of 2019 Rare Disease Day activities and the Rare Impact Awards 2019	Financial Support	United States	USD	\$	13,500.00	Yes
37	2019	Rare Diseases	National Organization for Rare Disorders (NORD)	Sponsorship for the production of three disease state education videos featuring sickle cell disease, beta-thalassemia and adrenoleukodystrophy	Financial Support	United States	USD	\$	45,000.00	Yes
38	2019	Sickle Cell	Metropolitan Seattle Sickle Cell Task Force	Support for the 14th Annual Walk/Bike for Sickle Cell in Seattle Washington	Financial Support	United States	USD	\$	2,000.00	Yes
39	2019	Sickle Cell	Sickle Cell Community Consortium	Support for the 6th Annual Sickle Cell Patient and Family Symposium	Financial Support	United States	USD	\$	20,000.00	Yes
40	2019	Sickle Cell	Sickle Cell Disease Association of America	Support for the Sickle Cell Disease Association of America 47th Annual National Convention	Financial Support	United States	USD	\$	25,000.00	Yes
41	2019	Rare Diseases	NTSAD - National Tay-Sach Association Diseases	Sponsorship for the Imagine and Believe Event hosted by the National Tay-Sachs & Allied Disease Association	Financial Support	United States	USD	\$	1,500.00	Yes
42	2019	Rare Diseases	National Organization for Rare Disorders (NORD)	Sponsorship for the production of the National Organization for Rare Disorders Gene Therapy Webinar Series	Financial Support	United States	USD	\$	10,000.00	Yes
43	2019	Rare Diseases	National Organization for Rare Disorders (NORD)	Support for the 2019 NORD Rare Diseases and Orphan Products Breakthrough Summit	Financial Support	United States	USD	\$	8,500.00	Yes
44	2019	ALD	ALD Connect	Support for ALD Connect's 2019 Annual Conference	Financial Support	United States	USD	\$	30,000.00	Yes
45	2019	Thalassemia	Greek Thalassemia Federation (EOTHA)	Sponsorship of the Panhellenic Informative Event about Thalassemia 2019 Conference	Financial Support	Greece	EUR	€	5,000.00	Yes
46	2019	Rare Diseases	BIO - Biotechnology Innovation Organization	Sponsorship of the 2019 BIO Patient and Health Advocacy Summit	Financial Support	United States	USD	\$	10,000.00	Yes
47	2019	Sickle Cell	Supporters of Families with Sickle Cell Disease, Inc.	Sponsorship of the 2019 6th Annual Sickle Cell Knocking Down Walls 5k Walk, Run or Jog	Financial Support	United States	USD	\$	2,000.00	Yes
48	2019	Sickle Cell	Sick Cells	Support for Sick Cell's Sickle Cell Ambassador Program to educate and equip ambassadors on policy issues	Financial Support	United States	USD	\$	25,000.00	Yes
49	2019	Sickle Cell	Greater Boston Sickle Cell Disease Association (GBSCDA)	Sponsorship of GBSCDA Walk Fundraising Event	Financial Support	United States	USD	\$	8,000.00	Yes
50	2019	ALD	Brian's Hope	Sponsorship of Brian's Hope's Twenty-third Annual Hammerfest Triathlon	Financial Support	United States	USD	\$	3,000.00	Yes
51	2019	Other	Massachusetts Biotechnology Council (MassBio)	Support for Mass Bio's 2019 Patient Advocacy Summit	Financial Support	United States	USD	\$	2,500.00	Yes
52	2019	Sickle Cell	Sickle Cell Foundation of Minnesota	Sponsorship for the Sickle Cell Foundation of Minnesota's 2nd Annual Sickle Cell-cebration of Hope Fundraising Gala	Financial Support	United States	USD	\$	500.00	Yes
53	2019	Sickle Cell	The Embrace Kids Foundation	Sponsorship of the 2019 Tackle Sickle Cell Casino Night to support sickle cell research and services for children and families with sickle cell disease	Financial Support	United States	USD	\$	5,000.00	Yes
54	2019	ALD	International Patient Organisation for Primary Immunodeficiencies (IPOPI)	Support for IPOPI's 2020 EU Newborn Screening Advocacy Programme	Financial Support	United Kingdom	EUR	€	20,000.00	Yes
55	2019	ALD	Hunter's Hope Foundation, Inc.	Sponsorship for Leukodystrophy Care Network's Clinical Care Coordination and Data Registry Training	Financial Support	United States	USD	\$	15,000.00	Yes

56	2019	Rare Diseases	Beyond The Diagnosis	Support of Beyond The Diagnosis's 2019 programs - Leadership trainings, update of website, newsletter and support patient empowerment events.	Financial Support	United States	USD	\$	25,000.00	Yes
57	2019	ALD	The Calliope Joy Foundation	Sponsorship for the 2nd Annual Cupcake Run to support leukodystrophy research	Financial Support	United States	USD	\$	500.00	Yes
58	2019	ALD	Fondazione Franco e Piera Cutino Onlus	Support for the pilot study "The Patient at the Centre" How to overcome the psychological burden of the disease.	Financial Support	Italy	EUR	€	11,500.00	Yes
59	2019	Thalassemia	Greek Thalassemia Association (ESTHA)	Support for the Greek Thalassemia Association's (ESTHA) 2019 Educational Meeting	Financial Support	Italy	EUR	€	3,000.00	Yes
60	2019	Thalassemia	Thalassamiehilfe Ohne Grenzen e.V.	Support of Thalassamiehilfe's 2019 programs - Leadership trainings, update of website, newsletter and support patient empowerment events	Financial Support	Italy	EUR	€	5,400.00	Yes
61	2019	ALD	Aidan Jack Seeger Foundation (AJSF)	Sponsorship for the AJSF 4th Annual Standards of Care Meeting	Financial Support	United States	USD	\$	40,000.00	Yes
62	2019	Rare Diseases	EveryLife Foundation	Support for Newborn Screening Activities and Rare Disease Week on Capitol Hill	Financial Support	United States	USD	\$	35,000.00	Yes
63	2019	Rare Diseases	Fondazione Giambrone	Sponsorship for Fondazione Giambrone patient education programs	Financial Support	Italy	EUR	€	14,550.00	Yes
64	2019	Thalassemia	The Swedish Blood Cancer Association	Sponsorship of the 2019 Swedish Chronic Blood Disease Day	Financial Support	Sweden	EUR	€	2,255.00	Yes
65	2019	Rare Diseases	MassBio - Massachusetts Biotechnology Council	Sponsorship of Rare Disease Day 2019	Financial Support	United States	USD	\$	3,500.00	Yes
66	2019	Thalassemia	UK Thalassemia Society (UKTS)	Sponsorship of their Patient Support Program and UKTS Magazine	Financial Support	United Kingdom	GBP	£	15,000.00	Yes
67	2019	Sickle Cell	Dreamsickle Kids Foundation	Support of Dreamsickle Kids Foundation's 2019 programs, leadership trainings, update of website, newsletter and support patient empowerment events	Financial Support	United States	USD	\$	1,000.00	Yes
68	2019	Rare Diseases	Genetic Alliance UK	Support of Genetic Alliance UK 2019 programs, leadership trainings, update of website, newsletter and support patient empowerment events	Financial Support	United Kingdom	GBP	£	2,000.00	Yes
	2019	Rare Diseases	Metabolic Support UK	Support of the "Patients with Access to Treatments and Specialist Services" program	Financial Support	United Kingdom	GBP	£	5,000.00	Yes