

Therapeutic Area	Name of Beneficiary Institution	Program/Project Description	Support Type	Country	Currency	Individual Payment Amount
ALD	Fundacion Lautaro te Necesita	Sponsorship of the Annual Meeting of Families with Leucodistrophies and Training of Health Professionals	Financial Support	Argentina	USD	\$ 7,500.00
Thalassemia	Thalassemia International Federation	Grant to support TIF Plan of Activities 2018: Educational platform, Train the Trainers workshop and Patients' Pocket Pal	Financial Support	Cyprus	EUR	€ 100,000.00
Thalassemia	Thalassemia International Federation	Sponsorship of TIF and European Institutions meeting: The Migration Challenge	Financial Support	Cyprus	EUR	€ 25,000.00
ALD	The Myelin Project	Sponsorship of the 4th Intl Symposium on MS & Myelin Disorders organized by the Myelin Project	Financial Support	Germany	EUR	€ 5,000.00
Thalassemia	EOTHA - Greek Thalassemia Federation	Sponsorship - Panhellenic Informative Event about Thalassaemia 2018 Conference	Financial Support	Greece	EUR	€ 5,000.00
ALD	AISMEE Italian Association for the Support of Hereditary Metabolic Diseases Onlus	Sponsorship of their 2018 Communication Campaign for awareness on extended neonatal screening	Financial Support	Italy	EUR	€ 4,500.00
Sickle Cell	Fondazione Italiana Leonardo Giambone	Sponsorship of Modena SCD Educational Event - SCD Daily care in Italy	Financial Support	Italy	EUR	€ 3,500.00
Thalassemia	Fondazione Italiana "Leonardo Giambone"	3 Thalassemia educational patient courses aimed to empower patients through a collaborative platform.	Financial Support	Italy	EUR	€ 7,000.00
Thalassemia	United Onlus	Support of UNITED's 2018 programs - Leadership trainings, update of website, newsletter and support patient empowerment events	Financial Support	Italy	EUR	€ 10,000.00
Thalassemia	Thalassa Azione Onlus	Sponsorship of Thalassa Azione 2018 Gala	Financial Support	Italy	EUR	\$ 1,000.00
ALD	ALD Life	ALD Life activities to advance awareness and education around Adrenoleukodystrophy Disease in the UK and Europe	Financial Support	United Kingdom	USD	\$ 130,000.00
ALD	ALD Life	Support of ALD Life's educational materials, design, writing and print, new website (build and design)	Financial Support	United Kingdom	GBP	£ 32,970.00
ALD	United Leukodystrophy Foundation	Sponsorship of the 2018 Scientific Symposium and Family Conference	Financial Support	United States	USD	\$ 10,000.00
ALD	Aidan Jack Seeger Foundation	Grant to create a guide for newly diagnosed ALD Newborn Screening Families	Financial Support	United States	USD	\$ 30,000.00
ALD	Brian's Hope	Sponsorship of Hammerfest Triathlon 2018	Financial Support	United States	USD	\$ 3,000.00
ALD	Aidan Jack Seeger Foundation	Sponsorship of the 3rd ALD Standards of Care Meeting	Financial Support	United States	USD	\$ 25,000.00
ALD	ALD Connect	Sponsorship of ALD Connect Annual Conference 2018	Financial Support	United States	USD	\$ 25,000.00
ALD	Ann & Robert H. Lurie Children's Hospital of Chicago	Sponsorship of First Leukodystrophy Patient and Family Education Event	Financial Support	United States	USD	\$ 2,500.00
Other	BIO	Sponsorship of 2018 BIO Patient and Health Advocacy Summit	Financial Support	United States	USD	\$ 10,000.00
Rare Diseases	MassBio	Sponsorship of Rare Disease Day 2018	Financial Support	United States	USD	\$ 2,500.00
Rare Diseases	Global Genes	Sponsorship of Rare Access to Critical Therapies (ACT) Stakeholder Summit	Financial Support	United States	USD	\$ 5,000.00
Rare Diseases	Beyond the Diagnosis	Sponsorship of The Beyond the Diagnosis Art Exhibit 2018	Financial Support	United States	USD	\$ 5,000.00
Rare Diseases	NTSAD - National Tay-Sachs & Allied Diseases Association	Sponsorship of the 2018 Imagine & Believe Event	Financial Support	United States	USD	\$ 750.00



## 2018 Patient Advocacy Spend

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Rare Diseases	MassBio	Rare Disease Day 2019	Financial Support	United States	USD	\$ 2,500.00
Sickle Cell	Next Step	Next Step Block Party Fundraising: Benefit and Celebrate the support of teens and young adults living with chronic life-threatening illnesses.	Financial Support	United States	USD	\$ 2,500.00
Sickle Cell	Sickle Cell Community Consortium	SCCC Leadership Summit - In attendance are Patients, Caregivers, Advocates, Allies and Community based organizations from across the USA.	Financial Support	United States	USD	\$ 20,000.00
Sickle Cell	Sickle International Family Coalition	Sponsorship of "Champions W/ Passion" event	Financial Support	United States	USD	\$ 1,000.00
Sickle Cell	Martin Center Sickle Cell Initiative	Sponsorship of 2018 Indiana Sickle Cell Conference	Financial Support	United States	USD	\$ 1,000.00
Sickle Cell	Cayenne Wellness Center and Children's Foundation	Sponsorship of the 10th Annual Sickle Cell Disease Educational Seminar	Financial Support	United States	USD	\$ 5,000.00
Sickle Cell	Jack and Jill of America	Sponsorship of their SCD Educational Event	Financial Support	United States	USD	\$ 1,500.00
Sickle Cell	Greater Boston Sickle Cell Disease Association	Sponsorship of GBSCDA Gala and Walk Fundraising Events	Financial Support	United States	USD	\$ 7,500.00
Sickle Cell	Sickle Cell Association of Texas Marc Thomas Foundation	Sponsorship of 2018 CellAbration camps to provide transportation, assistance and educational supplies	Financial Support	United States	USD	\$ 2,950.00
Sickle Cell	The Next Step Fund	Sponsorship of 2018 Tackle Sickle Cell Casino Night	Financial Support	United States	USD	\$ 5,000.00
Sickle Cell	Sick Cells	Sponsorship of Sick Cells stories program "Patient Stories of SCD"	Financial Support	United States	USD	\$ 10,000.00
Sickle Cell	Supporters of Families with Sickle Cell Disease, Inc.	Sponsorship of 5th Annual Sickle Cell 5k Run, Jog or Walk	Financial Support	United States	USD	\$ 2,500.00
Sickle Cell	Children's Healthcare of Atlanta Foundation, Inc.	Sponsorship of their 2018 Sickle Cell Education Day	Financial Support	United States	USD	\$ 3,000.00
Sickle Cell	Bold Lips for Sickle Cell	Support for the Sickle Cell HBCU College Tour	Financial Support	United States	USD	\$ 1,000.00
Thalassemia	Cooley's Anemia Foundation	Sponsorship of CAF Family Conference	Financial Support	United States	USD	\$ 25,000.00
Thalassemia	Cooley's Anemia Foundation	Sponsorship of CAF Gala	Financial Support	United States	USD	\$ 17,000.00
Thalassemia	Cooley's Anemia Foundation	bluebird participation in the CAF Care Walk 2018 - Thalassemia Day awareness walk.	Financial Support	United States	USD	\$ 15,000.00
Thalassemia	Cooley's Anemia Foundation	Sponsorship of CAF Care Walk for Thalassemia Day	Financial Support	United States	USD	\$ 7,500.00