

DANE, Living with hATTR Amyloidosis



CECE, Living with hATTR Amyloidosis



MARY, Living with an Acute Hepatic Porphyria



# Advocacy for Impact Grants

2018 RECIPIENTS

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## PROGRAM OVERVIEW

Advocacy for Impact Grants is a global competitive grants program for patient advocacy groups that aims to inspire solutions for critical unmet needs in the rare disease community. At Alnylam's core, we value and understand how exploring and developing new ideas has the potential to create high-impact initiatives that are a catalyst for change. Through Advocacy for Impact Grants, Alnylam seeks to support the ATTR amyloidosis, acute hepatic porphyrias and primary hyperoxaluria type 1 communities from around the world.

In the first year of the program, support has been awarded to seven patient advocacy groups in six countries within The Americas and Europe to help them bring their creative new projects to fruition.

This year's patient advocacy group recipients and their initiatives are:

### Amyloidosis Research Consortium, USA

The Amyloidosis Research Consortium is dedicated to improving survival rates and quality of life for people living with amyloidosis. The consortium's online Appointment Optimizer platform will help facilitate more effective communication between physicians and amyloidosis patients throughout the United States, including in traditionally underserved communities. This tool will allow patients to better understand their condition and adhere to their treatment plan.

### Brazilian Porphyria Association (Associação Brasileira de Porfíria), Brazil

The Brazilian Porphyria Association serves as the voice for people living with porphyria in Brazil and aims to create a better future for those impacted by the disease. The association's genetic screening program will help facilitate the identification of disease-causing mutations in patients with porphyria throughout Brazil, enabling much needed improvements in access to diagnosis and allowing the organization to reduce and prevent new crises in families and improve patient quality of life.

### Canadian Association for Porphyria (Association Canadienne de Porphyrie), Canada

The Canadian Association for Porphyria focuses on delivering evidence-based information and advocating for comprehensive care that supports patients with porphyria, their families and health care providers. Throughout Canada, there is a low level of awareness of porphyria and many physicians do not have the full understanding needed to provide high-quality care to porphyria patients. With this grant, the association will develop the Canadian Network of Porphyria Experts in order to improve diagnosis and treatment of porphyria patients while enhancing management, education and investigation of the disease.

### **FAMY Norrbotten, Sweden**

FAMY Norrbotten supports amyloidosis patients and their families by providing essential information about the disease to improve the care patients receive. The organization will implement a campaign to educate patients and health care providers about amyloidosis through the organization's activities in 10 health centers in Norrbotten and hospitals in Stockholm and Gothenburg, Sweden. This campaign will increase awareness of the disease throughout Sweden and allow doctors to make quicker and more accurate diagnoses.

### **Swiss Society of Porphyria (Schweizerische Gesellschaft für Porphyrie, SGP), Switzerland**

Schweizerische Gesellschaft für Porphyrie (SGP) is dedicated to promoting and safeguarding the interests of porphyria patients in Switzerland. There is a lack of knowledge in the medical community that has led to mistakes in the diagnosis of patients and a lack of awareness from the community at large. SGP invented the “Häm O` Globin and Family” figure — a cartoon style molecule used to simplify the way basic biochemical and medical processes are explained while highlighting key messaging around porphyria. Through this grant, SGP will expand the use of this figure and communication model through interactive presentations, social media and printed materials in order to better explain porphyria and maximize reach among the medical community and the community at large.

### **The Brazilian Association of Amyloidosis (Associação Brasileira de Paramiloidose), Brazil**

The Brazilian Association of Amyloidosis supports patients with ATTR amyloidosis by helping shape public policies surrounding amyloidosis and building awareness of the disease. Through this grant, the association will focus on the north-east and mid-west regions of Brazil — where there is little knowledge of amyloidosis and a large need for awareness surrounding the treatment and unmet needs of those living with the disease. The association will establish a regional patient support program that will equip volunteers with the tools necessary to launch and maintain their own local projects. These projects will provide a support system for patients and families, tailor advocacy efforts to the needs of each local community and create awareness of resources and support systems in place for the community at large.

### **The British Porphyria Association, UK**

The British Porphyria Association supports and educates patients, relatives and medical professionals about porphyria. Through this grant, the association will work towards engaging a younger cohort of porphyria patients for whom there is a lack of support and engagement — and highlighting the need for additional mental health support. An educational festival in Manchester, England will be held in celebration of the British Porphyria Association's 20th Anniversary to attract younger individuals through interactive activities held at various stages throughout the educational festival. Each stage will have a special focus that will build awareness, provide tools and resources and explore holistic approaches for coping.

Advocacy for Impact Grants is an annual program. More information for the 2019 program will be posted on [our website](#) later in the year.