



## Alnylam Announces Recipients of First Annual Advocacy for Impact Grants Program

February 28, 2019

– *Competitive Grants Program Recognizes New Projects that Impact the ATTR Amyloidosis and Acute Hepatic Porphyria Patient Communities* –

CAMBRIDGE, Mass.--(BUSINESS WIRE)--Feb. 28, 2019-- [Alnylam Pharmaceuticals, Inc.](#) (Nasdaq: ALNY), the leading RNAi therapeutics company, today announced support for seven patient advocacy groups through the *Advocacy for Impact Grants* program. This annual competitive grants program recognizes high-impact projects that address critical unmet needs in rare disease communities around the globe.

The grants support projects that will benefit acute hepatic porphyria and ATTR amyloidosis patient communities in six countries across The Americas and Europe. In its inaugural year the program will grant \$248,000 to support development and implementation of seven projects designed to increase disease awareness among patients and healthcare providers, improve patient quality of life and help patients receive faster, more accurate diagnoses.

“On this Rare Disease Day, we’re proud to announce the recipients of funding in our first annual *Advocacy for Impact Grants* program. The level of response from rare disease advocacy groups to this new program underscores the pressing challenges these patient communities face,” said Tiffany Patrick, Head of Global Patient Advocacy and Engagement at Alnylam. “In total, 26 organizations submitted proposals for consideration and the seven proposals selected for funding presented unique and thoughtful projects that look to reach diverse populations.”

2018 grant recipients include:

- **Amyloidosis Research Consortium, USA**– The consortium’s online Appointment Optimizer will improve communication between physicians and amyloidosis patients in the United States, allowing patients to better understand their condition and adhere to treatment plans.
- **Brazilian Porphyria Association (Associação Brasileira de Porfíria), Brazil**– 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 diagnosis and patient quality of life.
- **Canadian Association for Porphyria (Association Canadienne de Porphyrie), Canada**– The association will develop the Canadian Network of Porphyria Experts to improve diagnosis and treatment of porphyria patients.
- **FAMY Norrbotten, Sweden** – The organization will educate patients and healthcare providers about amyloidosis through an awareness campaign highlighted throughout health centers and hospitals in Sweden, allowing doctors to make quicker and more accurate diagnoses.
- **Swiss Society of Porphyria (Schweizerische Gesellschaft für Porphyrie, SGP), Switzerland**– SGP will expand the use of its popular science communication model to better explain porphyria among the Switzerland medical community and public in simplified terms.
- **The Brazilian Association of Amyloidosis (Associação Brasileira de Paramiloidose), Brazil**– The association will establish local patient support programs that will train volunteer networks in the Northeast and Midwest regions of Brazil to increase awareness of available resources for amyloidosis patients.
- **The British Porphyria Association, UK**– The association will hold an educational festival in Manchester, England to engage young porphyria patients and provide holistic coping approaches that support physical and mental health.

*Advocacy for Impact Grants* was open to patient advocacy groups around the world requesting funding for up to \$50,000 for new projects focused on the ATTR amyloidosis, acute hepatic porphyria and/or primary hyperoxaluria type 1 patient communities, and seeking to impact the communities in one of the following ways:

- Increase disease awareness and access to diagnosis;
- Offer education to patients, families, caregivers, healthcare providers and/or public; or
- Improve patient care.

For a full description of the 2018 grant recipients and their proposals, along with information about applying for 2019 *Advocacy for Impact Grants*, please [visit our website](#).

### About Alnylam Pharmaceuticals

Alnylam (Nasdaq: ALNY) is leading the translation of RNA interference (RNAi) into a whole new class of innovative medicines with the potential to transform the lives of people afflicted with rare genetic, cardio-metabolic, hepatic infectious, and central nervous system (CNS)/ocular diseases. Based on Nobel Prize-winning science, RNAi therapeutics represent a powerful, clinically validated approach for the treatment of a wide range of severe and debilitating diseases. Founded in 2002, Alnylam is delivering on a bold vision to turn scientific possibility into reality, with a robust discovery platform. Alnylam’s first U.S. FDA-approved RNAi therapeutic is ONPATTRO® (patisiran) lipid complex injection available in the U.S. for the treatment of the polyneuropathy of hereditary transthyretin-mediated (hATTR) amyloidosis in adults. In the EU, ONPATTRO is approved for the treatment of hATTR amyloidosis in adults with stage 1 or stage 2 polyneuropathy. Alnylam has a deep pipeline of investigational medicines, including five product candidates that are in late-stage development. Looking forward, Alnylam will continue to execute on its “Alnylam 2020” strategy of building a multi-product, commercial-stage biopharmaceutical company with a sustainable pipeline of RNAi-based medicines to address the needs of patients who have limited or inadequate treatment options. Alnylam employs over 1,000 people worldwide and is headquartered in Cambridge, MA. For more

information about our people, science and pipeline, please visit [www.alnylam.com](http://www.alnylam.com) and engage with us on Twitter at [@Alnylam](https://twitter.com/Alnylam) or on [LinkedIn](https://www.linkedin.com/company/alnylam).

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