

# Ionis and Akcea Recognize FCS Awareness Day With Global Community Efforts to Celebrate Unsung Heroes

November 6, 2020

BOSTON & CARLSBAD, Calif.--(BUSINESS WIRE)--Nov. 6, 2020-- Ionis Pharmaceuticals (NASDAQ: IONS) and its wholly owned subsidiary, Akcea Therapeutics, today recognize the 3<sup>rd</sup> annual Familial Chylomicronemia Syndrome (FCS) Awareness Day, a global observance held each year on the first Friday in November to build broader awareness of the challenges associated with this debilitating, ultra-rare disease. Together with members of the FCS community, Ionis and Akcea have made significant progress in efforts to help people around the world learn about FCS and the impact it has on patients, their families and caregivers.

This press release features multimedia. View the full release here: <https://www.businesswire.com/news/home/20201106005097/en/>

"We are proud to join forces with the FCS community to bring awareness to this devastating disease. Today, we shine a light on the patients, caregivers and families who live with the burden of this disease and we celebrate the members of the global FCS community who are leading the charge to drive awareness of FCS," said Kristina Bowyer, vice president of patient centric drug development at Ionis. "Advocates including Melissa Goetz and Lindsey Sutton from the FCS Foundation, and Jill Praver from Action FCS, are some of the many humble heroes whose tireless efforts to advocate on behalf of patients and families is inspiration for our work. Their strength and commitment, especially during a very challenging year, give our teams a renewed dedication to support their needs."

FCS is a genetic disease caused by impaired function of the enzyme lipoprotein lipase (LPL), which results in elevated triglyceride levels and significant risk and disease burden. This may include unpredictable and potentially fatal acute pancreatitis as well as chronic complications due to permanent organ damage. It is estimated that there are between 3,000 to 5,000 people living with FCS worldwide. Patients must manage their triglyceride levels by adopting a strict, extremely low-fat diet of 10-20g of fat per day, which is incredibly challenging and does not remove the risk of pancreatitis and other symptoms of the disease.

To drive attention to FCS Awareness Day, employees from both Ionis and Akcea will participate in an FCS diet challenge where they must adhere to the strict, low-fat diet that patients live by every day for the entire FCS Awareness Day. The companies also encourage employees and members of the global FCS community to participate in a recipe challenge where they can share creative recipes including FCS-friendly foods. Ionis and Akcea plan to share their activities on social media using hashtags #FCSAwarenessDay, #chylomicronemia, #ActionFCS, and #LPLD. The recipes are available [here](#).

"I have always lived with the challenges of the low-fat FCS diet and the impact it has had on me physically, emotionally and socially – I would often avoid social engagements with friends and family," said Krish, a London resident who lives with FCS. "I am grateful to companies like Akcea and Ionis for highlighting the unique challenges that people affected by FCS experience daily and their efforts to support patients. Together, we must continue to raise awareness of this challenging and debilitating rare disease on a global scale."

## About FCS

FCS is an ultra-rare disease caused by impaired function of the enzyme lipoprotein lipase (LPL) and characterized by severe hypertriglyceridemia (>880mg/dL or 10mmol/L) and a risk of unpredictable and potentially fatal acute pancreatitis. Because of limited LPL production or function, people with FCS cannot breakdown chylomicrons, lipoprotein particles that are 90 percent triglycerides. In addition to acute pancreatitis, FCS patients are at risk of chronic complications due to permanent organ damage, including chronic pancreatitis and pancreatogenic (type 3c) diabetes. They can experience daily symptoms including abdominal pain, generalized fatigue and impaired cognition that affect their ability to work. People with FCS also report major emotional and psychosocial effects including anxiety, social withdrawal, depression and brain fog. Additional information on FCS is available at [www.fcsfocus.com](http://www.fcsfocus.com), through Action FCS at <https://www.actionfcs.org/> and through The FCS Foundation at <http://www.livingwithfcs.org>. For a full list of organizations supporting the FCS community worldwide, please [click here](#).

## ABOUT AKCEA THERAPEUTICS, INC.

Akcea Therapeutics, Inc. is a wholly owned subsidiary of Ionis Pharmaceuticals, Inc. (NASDAQ: IONS), the leader in RNA therapeutics. Akcea commercializes TEGSEDI® (inotersen) and WAYLIVRA® (volanesorsen), and with Ionis, is advancing a mature pipeline of novel medicines discovered by Ionis and based on Ionis' proprietary antisense technology. TEGSEDI is approved in the U.S., E.U., Canada and Brazil, and WAYLIVRA is approved in the E.U. For more information about Akcea please visit [www.akceatx.com](http://www.akceatx.com).

## ABOUT IONIS PHARMACEUTICALS, INC.

As the leader in RNA-targeted drug discovery and development, Ionis has created an efficient, broadly applicable, drug discovery platform called antisense technology that can treat diseases where no other therapeutic approaches have proven effective. Our drug discovery platform has served as a springboard for actionable promise and realized hope for patients with unmet needs. We created the first and only approved treatment for children and adults with spinal muscular atrophy as well as the world's first RNA-targeted therapeutic approved for the treatment of polyneuropathy in adults with hereditary transthyretin amyloidosis. Our sights are set on all the patients we have yet to reach with a pipeline of more than 40 novel medicines designed to potentially treat a broad range of disease, including neurological, cardio-renal, metabolic, infectious, and pulmonary diseases. To learn more about Ionis, visit [www.ionispharma.com](http://www.ionispharma.com) and follow us on Twitter @ionispharma.

## FORWARD-LOOKING STATEMENT

This press release includes forward-looking statements regarding Ionis' business, financial guidance and the therapeutic and commercial potential of WAYLIVRA and Ionis' technologies and products in development, including the business of Akcea Therapeutics, Inc., Ionis' wholly owned subsidiary. Any statement describing Ionis' goals, expectations, financial or other projections, intentions or beliefs is a forward-looking statement and should be considered an at-risk statement. Such statements are subject to certain risks and uncertainties, including those related to the impact COVID-19 could have on our business, and including but not limited to those related to our commercial products and the medicines in our pipeline, and particularly those inherent in the process of discovering, developing and commercializing medicines that are safe and effective for use as human therapeutics, and

in the endeavor of building a business around such medicines. Ionis' forward-looking statements also involve assumptions that, if they never materialize or prove correct, could cause its results to differ materially from those expressed or implied by such forward-looking statements. Although Ionis' forward-looking statements reflect the good faith judgment of its management, these statements are based only on facts and factors currently known by Ionis. As a result, you are cautioned not to rely on these forward-looking statements. These and other risks concerning Ionis' programs are described in additional detail in Ionis' annual report on Form 10-K for the year ended December 31, 2019, and the most recent Form 10-Q quarterly filing, which are on file with the SEC. Copies of these and other documents are available from the Company.

Ionis Pharmaceuticals® is a trademark of Ionis Pharmaceuticals, Inc. Akcea Therapeutics®, TEGSEDI® and WAYLIVRA® are trademarks of Akcea Therapeutics, Inc.

View source version on [businesswire.com](https://www.businesswire.com/news/home/20201106005097/en/): <https://www.businesswire.com/news/home/20201106005097/en/>

**Akcea/Ionis Investor Contact:**

D. Wade Walke, Ph.D.  
Vice President, Investor Relations  
760-603-2741  
[wwalke@ionisph.com](mailto:wwalke@ionisph.com)

**Akcea/Ionis Media Contact:**

Roslyn Patterson  
Vice President, Corporate Communications  
760-603-2681  
[rpatterson@ionisph.com](mailto:rpatterson@ionisph.com)

Source: Ionis Pharmaceuticals and Akcea Therapeutics