

Hide and Seek Foundation/SOAR



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Mission

The purpose of the Hide and Seek Foundation is to find treatments and cures for lysosomal disease as well as raise awareness of lysosomal disease as a major group of genetic disorders of children that cause mental retardation, seizures, crippling illness, liver and other organ failure, and premature death. At present, the Hide and Seek Foundation is focused on one of these diseases, Niemann-Pick Type C (NPC). It works to support critical, cutting-edge scientific research to cure NPC through the Support of Accelerated Research (SOAR)-NPC research collaborative.

Strategy/Approach

The Hide and Seek Foundation has developed a virtual biotech model for rare disease therapy development, focusing on NPC as a prototype.

Considered an “ultra-orphan disease,” approximately 250 patients have NPC in North America. There is currently one off-label treatment that seems to slow progression of the disease but no effective therapies or cures and no serious interest from industry in developing them.

By focusing on NPC through the SOAR collaborative, the foundation hopes to create a scalable treatment development model for other lysosomal diseases.

Research Portfolio

The SOAR Project is designed to find a cure for NPC. SOAR was created by parents and scientists as a grassroots response to the absence of treatments for this terminal disease. The SOAR collaborative is comprised of scientists from leading institutions where NPC research is conducted, including the Albert Einstein College of Medicine, Washington University of St. Louis, Mt. Sinai School of Medicine, and Oxford University, as well as advisors from the Mayo Clinic and the National Institutes of Health (NIH). Collaborators work closely with the NIH and other funders to leverage research investments. By focusing on compounds that do not need new approval by the Food and Drug Administration, in three years SOAR has accomplished a trial to test a treatment that could slow the progression of NPC. Conducted at the NIH, the trial validated a biomarker – a biological indicator of the disease's progression.

Partnership Practices

The foundation collaborates with scientists, families, foundations, and NIH. Other funders of the SOAR project include Hadley Hope, Addi & Cassi Fund, Dana's Angels Research Trust, and Race for Adam.

It is unclear whether the foundation partners with biotech and pharmaceutical companies. John Curd, MD, of Threshold Pharmaceuticals is on the SOAR advisory committee, but *FasterCures* was unable to locate any additional information about the organization's corporate relationships.

Financials

The foundation is a 501(c)(3) nonprofit health organization. The most recent financial information available is from 2010.¹

Year ending 12/31/10:

- Revenue: \$322,576
- Assets: \$120,256
- Grants: \$465,800 for 8 grants (\$7,500 to \$90,000)
- Gifts received: \$322,406
- Expenditures: \$543,268
- Total giving: \$465,800

According to a November 2011 **presentation** by SOAR project funder Jonathan Jacoby, in its second year, SOAR spent approximately \$700,000 on grants to four labs and one project manager.

Key Accomplishments

- One biomarker being validated and three under development.
- Four promising existing compounds in various stages of being developed/repurposed; at least one promising nutraceutical.

Leadership

- **SOAR Coordinator:** Ron Browne, PhD
- **SOAR Investigator and Professor of Neuroscience, Albert Einstein College of Medicine:** Steven Walkley, DVM, PhD, steve.walkley@einstein.yu.edu
- **CEO, The RARE Project and SOAR Funder, Hide & Seek Foundation:** Jonathan Jacoby, jonathan@abujj.com

¹ Information obtained from Foundation Center Directory, <http://fconline.foundationcenter.org>, May 2012.