Accelerated Cure Project for MS (ACP)

Founded in 2001 by Art Mellor

Evidence Data Open-Access Research Biosamples No Barriers MS

ACP Repository Community
ACP Repository Experience

• Does data sharing present a particular disadvantage for companies with little revenue and few products and deter venture capital needed to develop a product?

 Multiple companies (Diogenix, MSDx, Protagen, Somalogic, Glycominds…) have accessed ACP’s clinical data/biosamples and are willing to share resulting data because of the substantial cost savings of accessing the data/biosamples

“Working with (ACP) allowed us to obtain critical samples and confirm our results ... If I had to obtain these samples from scratch, it would have cost $1 million and added 5 years to the project.”

- Thomas M. Aune, PhD, Molecular Biology, Vanderbilt U. School of Med.
(from blogs.scientificamerican.com, May 7, 2013)
ACP Repository Experience

• What measures might be taken by all stakeholders to overcome the challenges experienced in sharing data?

➢ Invest in the “end-to-end” solution infrastructure to create a compelling value proposition for sharing data

➢ Key elements (ACP example)

  • “Honest broker” role – engages investigators
  • Study coordinator provision – engages patients
  • Data/sample distribution oversight committee
  • Date for return of results enables IP protection decision
  • Demonstrate or create the value proposition
ACP Repository Experience

• How can data sharing be framed as a positive attribute to encourage investment and participation in clinical trials?

➢ Deliver something back to the investigators and research community that could only come from data sharing and has substantial, unique value (ACP Matchmaker example)

Data Stacks

Colors = Research Studies
Circle Area = Number of Samples

Data Stack is the results from multiple research groups which have studied samples from the same patient IDs
Bridging Patient Power, Clinical Research and Data Sharing

Patients are Impatient
How Can We Help?