The Future of the Alpha-1 Foundation Research Registry

By Mike Graves

The Alpha-1 Foundation Research Registry has been promoting research throughout the Alpha-1 community for over a decade. The Registry has enrolled more than 4,200 Alphas and carriers of the Alpha-1 gene since 1997 and assisted in 84 research studies. The purpose of the Registry is to match the appropriate Alphas and carriers with current research projects in an attempt to develop Alpha-1 treatments and an eventual cure.

While we plan to continue the current structure of the Registry, we also want to meet the needs of researchers who have been asking us for additional and more accurate data from the Registry for some years. That’s why we have begun to build a Clinical Resource Center (CRC) Alpha-1 Registry.

We hope that the CRC Registry will eventually use most of the Alpha-1 Foundation’s Clinical Resource Centers across the United States. CRCs specialize in patient care and education for those with Alpha-1. Some CRCs treat lung disease, others liver disease. There are more than 70 CRCs, and more are being added all the time.

To see a list and contact information for Foundation CRCs across the country, visit the Foundation website at www.tiny.cc/Alpha-1CRC.

We believe that working with both Alphas and CRCs can bring two great results: Many Alphas can find a Clinical Resource Center near their home where they could visit an Alpha-1 expert yearly; and Registry data can be more complete and accurate.

HOW A CRC REGISTRY WOULD WORK:

The Medical University of South Carolina will provide the database to cross-index all the information that accumulates through the coming years.

We also need an easy-to-use tool to gather all this information. Fortunately, we have that. In 2008, the National Institutes of Health launched a new program called the Clinical Translational Science Awards (CTSA). About half of current CRCs have a CTSA award that pays for computer programs to make data collection easy. REDCap (Research Electronic Data Capture) is a convenient system that is similar to the popular public site SurveyMonkey — except that the REDCap information is encrypted to assure confidentiality of personal health information.

We also need a convenient way to find and use the stored data. MUSC is one of more than 33 medical centers (including some in Europe) who use a program called Integrated Informatics for Biology at the Bedside (called “i2b2” for short). This computer program allows data that contains no personally identifying information to be kept in a public database where it can be queried by anyone in the community.

We are planning a pilot study involving several of the CRCs that already have the capacity, to make sure the system will work the way we want it to. Lastly, we will need to fill up our database with Alphas who will visit their nearby CRCs, where healthcare professionals will collect and add the information we need — clinical data, images and biological samples to add to the new CRC Registry.

We are working as fast as we can to get the new CRC Registry up and running. We believe the summer of 2012 is the most likely start date.

Eventually, current Registry members will receive a mailed invitation to join the new CRC Registry. To join, you would make an appointment to visit the nearest Clinical Resource Center. From there a healthcare professional would have you sign a consent form and enter your data into the data warehouse. The data will be checked, made confidential and secure. The final output, with no personally identifying information, will be an open access database full of clinical Alpha-1 measurements. (Open access means the data is public, available to researchers all over the world.) The open access database is the critical component in improving the resources for research in Alpha-1.

Translational medicine is the practice of moving research projects from the laboratory into the clinic, where people affected by Alpha-1 might benefit. The additional, more detailed data will be a useful resource for researchers to formulate new projects and hopefully lead to a cure for Alpha-1.
An alpha tells about volunteer for a research study
IF YOU ARE A COMMUNITY-BASED GROUP OR A COMMUNITY ORGANIZATION: If you have been delivering health care in your community for some time, you may have noticed that your programs have not been reaching the people you intended. You may find that your efforts are not as effective as you had hoped. You may be concerned that your programs are not reaching the people who need them the most. You may be wondering how you can improve your programs to better meet the needs of your community.

IN THE PROVINCE OF ALBERTA: The province of Alberta is committed to improving access to health care for all Albertans. They have developed a strategy to improve health care in underserved communities. They have identified several key areas where they need to focus their efforts.

1. Identification of underserved communities: The province of Alberta has identified several communities that are underserved. They have developed a strategy to improve access to health care in these communities.

2. Development of community-based programs: The province of Alberta has developed community-based programs to improve access to health care in underserved communities. These programs are designed to be delivered in a way that is culturally appropriate and responsive to the needs of the community.

3. Partnerships with community organizations: The province of Alberta has partnered with community organizations to improve access to health care in underserved communities. These partnerships allow the province to leverage the resources and expertise of the community organizations to deliver effective programs.

4. Evaluation of programs: The province of Alberta is committed to evaluating the effectiveness of their programs. They are using data and feedback from community members to ensure that their programs are meeting the needs of the community.

THE PROGRAMS ARE DESIGNED TO...

1. Increase access to health care in underserved communities
2. Provide culturally appropriate programs
3. Partner with community organizations
4. Evaluate program effectiveness

The province of Alberta is committed to improving access to health care for all Albertans. They are working to ensure that everyone has access to the health care they need.

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Two Student Perspectives on Alpha-1

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To learn more about the importance of early detection and the impact it can have on your health, consider volunteering for the study.

Learn more at www.cancer.org/study.

Know Your Letters: Your Alpha-1 Letters

CFR specialists discuss future of research and family testing