



## CADASIL Association Board of Trustees Meeting Minutes



04-15-13

7:30PM EST

Teleconference Via FreeConferenceCall.com

In attendance: Anne McGuinness, Janet Mills, Barbara Hunt, Freddie Schilling, Christi Lushbaugh, Devin Lushbaugh, Alice Lindahl

### Annual General Membership Meeting

#### A. Update on Accomplishments 2012

Anne provided a review of activities and accomplishments achieved during 2012. April 24, 2012, we applied to incorporate in New Jersey and then began filling out the IRS forms for non-profit status. At the same time the original members were recruiting Board Members (called Trustees in NJ) to fill out the positions on the Board. In August, we applied for our tax-exempt status as 501c3 and were approved in September as 501c3, tax-exempt, non-profit public charity retroactive to April 24, 2012. We drafted and approved bylaws, which are available to members on the CADASIL Association website under the "About Us" tab. Original monies were donated by the original Trustees to cover start up costs.

Janet and Karla began publishing EMBRACE, the CADASIL Association bimonthly newsletter that is provided to members and published on our website. Many individuals attended the wonderful conference in Salt Lake City, hosted by the Russell family. November 16, we raised awareness by promoting CADASIL Awareness Day. Anne McGuinness, Barbara Hunt, Janet Mills, Karla Smith all went to D.C. and attended the activities around Rare Disease Day in February 2013. The RDLA (Rare Disease Legislative Advocates) provided a forum to meet with our state representatives from Congress or their assistants and discuss issues important to the Rare Disease community. We have been busy networking with other organizations like NORD, Genetic Alliance, Global Genes Project, and others to learn and raise awareness of CADASIL and make ourselves known. Many of these groups have been very helpful to us in our start up. We will need more people involved in Rare Disease Day and Week in DC and across the nation.

#### B. CADASIL Association Board:

Anne McGuinness	- President
Barbara Hunt	- Vice President and Treasurer
Janet Mills	- Secretary
Gail Hunt	- Trustee
Christi Lushbaugh	- Trustee
Nancy Maurer	- Associate Trustee
Karla Smith	- Associate Trustee
Pamela Russell	- Associate Trustee

Anyone interested in becoming a trustee is welcome to apply. Please read the bylaws first as they explain the positions and their responsibilities.

### C. Future Plans 2013

The CADASIL Association decided to host a conference in Boston June 27 and 28, 2013 with our scientific board. We are hoping for a good turnout and asking people to register on line at [CADASILAssociation.org](http://CADASILAssociation.org) or send an email to [info@cadasilassociation.org](mailto:info@cadasilassociation.org).

Our Annual Report will be available on our website, [CADASILassociation.org](http://CADASILassociation.org) after April 30.

Do not forget the Minnesota Motorcycle Run and Spaghetti Dinner in June! Please support Bob's efforts on FB and by spreading the word.

Alice shared that her family is taking a break from fundraising for a bit but are exploring some new ideas for the future.

If you have any questions or comments for the CADASIL Association, please email us at [info@cadasilassociation.org](mailto:info@cadasilassociation.org). We welcome help from anyone who wants to further our efforts to help patients with CADASIL. We need volunteers for many roles so feel free to offer your talents!

Meeting adjourned at 7:49pm E.S.T.

This meeting was recorded.

Notes respectfully submitted by Christi Lushbaugh