



2018 Rare Patient Impact Grant: Building a CADASIL Community

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BACKGROUND

- To provide meaningful, lasting, and accessible CADASIL information the CADASIL Connection Webinars were developed and launched in August 2017
- Researchers and clinicians invited to present their work in CADASIL
 - The objective of the webinar series is to “educate and connect the audience of researchers, clinicians, and patients on current research and developments in CADASIL”
 - 3 live webinars in Aug, Oct, Dec 2017
 - Due to the success of the first webinar, cureCADASIL applied for a Global Genes Impact Grant to achieve the following 3 goals:
 - Ensure short-term success by ensuring we had the financial capability to continue webinar series throughout 2018 with anticipated growth in interest
 - Expand on success by developing a new webinar ‘CADASIL Care’ focused on areas of interest to patients and families
 - Ensure long-term success and accessibility by increasing the capability of our other IT platforms

INITIATIVES

CONTINUE AND EXPAND CADASIL CONNECTION WEBINAR SERIES

- Two additional live webinars hosted in February and April 2018
- Use of GoToWebinar standard features, including:
 - Required registration for attendees (name, email address), with optional fields (profession, questions for researcher)
 - “Handouts” and questions via the chat function available to attendees during the webinar to increase attendee interaction
 - Post-webinar survey closed caption/muting
 - Webinar reports and recording (for download, long-term storage)
- Expand webinar platform capacity to allow for >100 attendees, if needed
- Expand capacity of other technology platforms, including:
 - Email capacity through Constant Contact
 - Webmaster support to allow access to recordings from website
 - Professional graphic support

Webinar software was critical to continue to expand our reach in the CADASIL community and to ensure sustainability of access to the recorded webinars in the future.



Fig 1: Graphic for CADASIL Connection

INITIATIVES *continued*

CREATE NEW WEBINAR SERIES in 2018: CADASIL CARE

Webinar platform has unlimited number of webinars during subscription period, allowing us to build on success and create a second webinar series.

CADASIL Care Webinars

- Dedicated to topics of interest to CADASIL patients, families, caregivers
- Community polled for areas of interest (Table 1)
- New webinar to be launched Fall 2018 (Figure 2)

Table 1: Community Survey Responses for CADASIL Care Webinar Topics

Webinar Topic	# of responses	% of responses
Cognitive impairment & dementia	19	22%
CADASIL and diet	17	20%
Understanding clinical trials	15	17%
Palliative care issues and planning ahead	10	12%
Genetic testing and genetic counseling before/after diagnosis	10	12%
Understanding the CADASIL Family Registry	8	9%
Advocacy training - How to be a CADASIL advocate	7	8%

Webinar platform includes unlimited number of webinars during subscription period, allowing us to build on success and create a second webinar series without additional cost.



Fig 2: Graphic for CADASIL care webinar

INCREASE WEBSITE CAPABILITY AND INTERACTIVITY

Other upgrades to support engagement of the CADASIL community included:

- Web hosting change and switch to Word Press website template (due to outdated and difficult to use previous website)
- Development of new web pages for both CADASIL Connection and CADASIL Care webinars for accessibility; New graphic for CADASIL care
- SSL security upgrade
- Making website responsive for ease of use on different devices
- Implementation of Google Analytics
- Website contact form for the community to share their CADASIL story
- Map of US providers with search function and patient submission form

RESULTS / OUTCOMES

CADASIL Connection webinar led to:

- Community education via attending live webinars or via recordings

Engagement via recordings exceeded attendance at live events, allowed for multiple viewings and long-term accessibility (Figure 3).

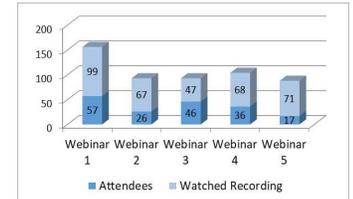


Fig 3: Viewings of Each Webinar

- Opportunities for engagement with researchers/clinicians
- Increased contacts, including patients, families, researchers/clinicians, pharma (Figure 4)

Other outcomes:

- Increased engagement via Facebook with + 122 followers
- 227 visitors to new webinar info and recordings page



Fig 4: Increase in Contacts Over Time

LEARNINGS

Just Do It!

- Webinar series was announced once we had 2 committed presentations
- Upfront work and cold calls/emails to researchers
- “Snowball effect” - researchers/clinicians who joined each webinar became interested in presenting at future webinars

Marketing

- Most effective via multiple channels: website, emails, social media, rare disease umbrella organizations, and umbrella disease organizations
- Presenter sharing the webinar event with his/her colleagues was effective at increasing attendance
- Sharing webinar recording with registration link led to growth
- Follow through is key but be prepared to work!

Moved to pre-recorded webinars instead of live webinars in order to:

- Ease time burden on volunteers which ultimately will lead to more recorded events
- Expand to include international presenters from different time zones