

SOMETHING BETTER THAN HOPE

Patient Advocacy and
Community Engagement

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December 1, 2021

CIRM
CALIFORNIA STEM CELL AGENCY

Past Patient Advocate Outreach Efforts

- In person presentations at individual support group meetings.
- In person presentations at conferences organized around specific diseases or at rare disease/umbrella events.
- Online presentations/discussions via Google Hangout, Facebook Live, Zoom etc.
- Email blasts to individuals from our Stem Cell Champions email list (1,600 so far) who specified an interest in a particular disease.

Past Patient Advocate Outreach Efforts

Message:

- Disease specific
- CIRM funding for that disease/condition
- Other funding for that disease/condition

Community Engagement NOW

New Messaging:

- Positions us as trusted source of information.
- Listens to the communities and doesn't adopt a one-size-fits-all approach.
- Asks communities what they want from us: information, support, resources.
- Provides information on CIRM funded or Alpha Clinic sponsored clinical trials
- Offer guidance about stem cell tourism
- Consistent flow of information in order to maintain relationships and build trust
- Rely on local & community-based media and radio/tv to communicate our message

Community Engagement NOW

- Budget to hire a consultant with experience working in community engagement/outreach/organizing
- Establish best practices
- Make introductions
- Provide feedback