



Action CIND Accomplishments in Year 1

Action CIND's first year of operation has been eventful. The following is a high level summary of the many activities we've been involved with in the past year.

- ✓ We completed the paper work, formed a Board of Directors and became an incorporated non-profit in February. The Board holds a monthly conference calls and has had two in person sessions.
- ✓ We submitted our application to become a Charity in March. This was a very challenging and enlightening initiative. It's also a very long process expected to take over a year.
- ✓ We organized a number of activities for May 12th International Awareness Day. Our largest event was a health fair in Richmond Hill. We estimated at least 100 people attended. We considered it quite successful. Videos are available on Vimeo under Action CIND. We've started the planning for our 2017 event.
- ✓ We launched several social media accounts (e.g. Facebook, Twitter, Instagram, Pinterest, and Google+). We're pleased our Action CIND Facebook page has grown to 330 Likes and our May12th Facebook page now has over 21,800 followers.
- ✓ We responded to the CIHR refusal to adopt the proposal submitted by Canadian experts with no response.
- ✓ We also wrote to CIHR to ask that they attend the upcoming IACFS/ME conference with no response. We joined with a group of organizations to once again ask that they send a representative to the conference. CIHR finally confirmed they would attend. We had a patient represent us at the conference.
- ✓ We worked on developing our brand and design standards.
- ✓ We created a draft Strategic Plan for the next 5 years. It will be reviewed annually. It will be finalized once we have completed year one and achieved charitable status.
- ✓ We are working with a group of individuals to create a course on ME for Alberta patients. We hope we will then be able to take the final product and promote it in other places across Canada. The target is spring 2017.

- ✓ On Oct 1st we attended the outdoor Brechin Scarecrow Festival and had a booth for Action CIND to help educate people about the CIND illnesses. Over 1000 people attended the festival. We used our mascots Ben and Milo to help draw attention to our booth. They were excellent ambassadors and we'd estimate 90% of the attendees stopped to see them and saw our signs. Several engaged in conversation with us about CIND illnesses and we received a few donations. We made some good connections and several people took our membership form so overall, we think it was successful.
- ✓ We have struggled with our website but we are now on a path to have a much improved version to be implemented April 2017. Our www.May12th.org site is also getting some attention.
- ✓ We are looking at better ways to send emails and to communicate with members and volunteers.
- ✓ We have done software reviews for products to help us manage a large team of volunteers and activities. A package will be selected and implemented in April 2017.
- ✓ We've started up a Google AdWords account which will help to address our target markets. More advance work will be done once the website is updated.
- ✓ We have brought two support groups under our umbrella. We are managing the Scarborough group and the North Toronto Fibromyalgia group and plan to offer them more support in 2017. We also started investigating the feasibility of starting up two new groups. Our CEO visited Toronto area supports groups to introduce Action CIND to their members.
- ✓ We arranged for our supporters to have a bursary to help defray costs of participating in an online support group.
- ✓ We arranged for our supporters to have access to legal counsel for a free consultation for disability coverage. We also arranged for an Ontario disability consultant to assist patients for a reduced rate. Our consultant will also review legal bills for double billing.
- ✓ We have an individual in training to support a toll free help line. It's planned to launch in the 2nd quarter of 2017.
- ✓ We initiated a project CIND: A Visual Essay to help patients tell their stories through words and photography.
- ✓ We've begun work on a project to identify and help support groups in Canada.

- ✓ Our volunteer base continues to grow. We have attended two youth recruiting expos. Attending these events gave us good exposure to the general public as well as recruiting energetic youth to assist us.
- ✓ In anticipation of approval of our charity status, we've begun to develop approaches to fund raising and researching grants. We were successful with one grant application but unfortunately unsuccessful with a second grant application.
- ✓ We have participated in Georgian College's Henry Bernick Entrepreneur Centre's BUILD program and are developing our business plan. We participated in their 5 minute Pitch competition which gave us exposure and the opportunity to network.
- ✓ We participated in several business courses offered by our local Community Development Corporation (CDC). These courses have helped us to better manage the organization.
- ✓ We initiated an MP project where we plan to engage MP's to help us with a National Strategy for CIND illnesses.
- ✓ We've started work on a "How to Guide" for CPP Disability. A number of guides are planned for 2017.
- ✓ We initiated work on curating information about existing services in Canada for CIND patients.
- ✓ We've established a connection with a core group of Canadian doctors and researchers and established a team to help advance research in Canada. 3
- ✓ We have created teams to support us in the following areas:
 - general research
 - statistics and data collection
 - social media
 - volunteer coordination and standards
 - special projects (e.g. MP Package, Ombudsman, Charity Standards)
 - professional advisors (e.g. medical, legal, nursing, patient reps)
 - annual May 12th International Awareness Day activities
 - operations and support services
 - IT support (e.g. websites, software evaluation/implementation)
 - strategic planning and business model
 - graphics
 - support Groups