

## OUR MILESTONES - HISTORY

This Mile Stone web page is dedicated to letting you, our web site visitor and potential donator, understand what we have accomplished since being provided our non-profit status, 501c3, in 2001. It's been a long , hard journey that our Founder could have easily given up on, but her dedication to patients and dystonia has and remains committed even as new ventures begin for her outside the arena of dystonia.

### **Our Milestones :**

- **1985** American ST Association forms.
- **1989** Hemifacial spasms, jaw grinding and tics begin surfacing.
- **1992** While in Europe, our founder Beka notices she has developed symptoms of cervical dystonia.
- **1994** Beka serves as Secretary for NSTA , which is short lived as the group splits into 2 entities now known as [www.torticollis.org](http://www.torticollis.org) and [www.spasmodictorticollis.org](http://www.spasmodictorticollis.org) .
  - ANDA- Coalition formed by Allergan, Inc., in hopes of forming one universal dystonia group, is also short-lived and not endorsed by all groups.
  - [WeMove](http://www.wemove.org) arrives on the scene.
- **1998** Our Founder becomes a consultant for [www.athenadiagnostics.org](http://www.athenadiagnostics.org) as the discovery of the DYT1 gene is publicized by scientists.
  - A chapbook of poems "Dystonia is " is contributed to the DMRF.
  - Our Founder attends the International Dystonia Symposium in Victoria, BC, Canada.
  - Text for "I'm Moving Two" is written in 3 days and published. [Excerpts online now.](#)
  - The vision for multidisciplinary care begins to formulate in our Founders' mind along with a Board of Directors, to include exclusively active practicing nurses and allied healthcare professionals.
- **1999** She, along with Deb Holton, Esq. aka Spazz, begin an online chat support group, eventually, becoming part of [www.wemove.org](http://www.wemove.org) online chat rooms.
  - NBC airs the struggles of our Founder on *Dateline* in October.
  - The Airing is the first time EVER that dystonia is presented to the public by the media on a national level.
  - Beka begins volunteering for the [Bachmann-Strauss Fd.](http://www.bachmannstraussfd.org) in NYC , while continuing to work FT as an ICU nurse at New York Presbyterian.
- **2000** Together with her Board of Directors, ByLaws are formulated and nonprofit status is sought officially to begin the process of Setting the P.A.C.E.
  - A donation of \$1,300 from the local NSTA Washington, DC chapter helps our Founder develop a website breaking slowly into the framework of the Dystonia scene.
  - Since then, the yearly salary of Our Founder ,as an Open Heart RN within Manhattan, is used to offset overhead costs. This still continues even today for C4D.
  - Care4Dystonia, Inc. does accept voluntary donations, but does not publicly solicit monies from patients or support groups on a formal, regular basis.
  - I'm Moving Two...Are U ? is released as a 263 page book of prose.
  - [MyoBloc](http://www.myobloc.com) receives FDA approval for use in ST in Early December.
  - [Botox](http://www.botox.com) receives FDA approval for cervical dystonia treatment in mid December.
- **2001** 501c3 nonprofit status is obtained by Care4Dystonia, Inc. by the IRS.
- **2002** Additional media /inprint stories about dystonia are secured by our Founder.
  - See our entire media list 1998 to 2006 - [contact us via infoc4d@aol.com](mailto:infoc4d@aol.com).
- **2003**
  - Public awareness continues on the part of C4D
- **2004-5**
  - Our Founder undergoes DBS
  - Foto essay on DBS created [www.parasphotography.com/beka.html](http://www.parasphotography.com/beka.html)
  - NBC Nightly News covers Bekas' DBS Surgery and progress
  - CBS News covers Kaplitt and Beka.
  - Dr. Mike Kaplitt joins C4D as Science Advisor
  - Additional media - TV, print, online- coverage continues
  - Repeat Dystonia Care Survey completed
- **2006-7**
  - Virtual Magpie revamps C4Ds website
  - In Motion Newsletter re-airs online
  - Magnet Awareness program initiated
  - Cosmo Awareness Postcard Program begun at Weill-Cornell MC.
  - You Tube Are U at Risk ? Video developed online
  - Cosmo Awareness Ad developed

- Our Publications go online.
- Hunter College CUNY features our Founder during Commencement.
- Newly developed tri-fold brochures are created and distributed worldwide
- Our Stories of Hope become a groundbreaking web page for others to share their stories as well as reproduction by other web sites.
- ST Survey completed Oct 2007
- [LIM Campaign Coalition](#) Membership maintained
- HON Code Status maintained
- Monthly EMail Alerts initiated
- By Dec 2007 , over 62k unique visitors visit the web site.
- Social networking begins via
  - [YouTube](#)
  - [Facebook](#)
  - [Flickr](#)
  - [Plaxo](#)
  - [MySpace](#)
  - Yahoo360
- Donation page updated, results in unexpected donations!
- [Dr. Oz meets dystonia](#) on XM Radio Interview in Nov 2007
- Pain and Nutrition web pages expanded.
- **2008**
  - Grants obtained from: [Solstice Neurosciences, Inc.](#), [Allergan, Inc.](#) and [Mentor Corp.](#)
  - Kids in Motion created with Pen Pal alliances sent to [www.drcentral.com](#) and [www.tylershope.org](#)
  - Repeat On Air with Dr.Oz !
  - Dystonia Education Forum begun online at <http://community.wegohealth.com/group/dystonia>
  - Alliance with the [National Pain Foundation](#).
  - Media, media, media and dystonia as a disability.
  - [Redbook](#) Inspiration Nominee.
  - Loreal Women of Worth Nominee.
  - [www.aleve.com](#) commercial submission
  - Johnson/Johnson Discover Nursing Campaign profile
  - [Top 55 DBS Questions](#) goes abroad to the EU as a brochure !
  - Nurse E-Zine - Accommodating for Dystonia Feb 2008
  - Clarifying DBS Editorial Nursing Spectrum March 2008
  - Dystonia Screensaver Slide Show-Downloads
  - Journal of Neuroscience Nursing Article
  - Neurology Now June Editorial
  - [Buckley Broadcasting Alice Cooper PSAs released in April](#)
  - Oz Radio Show DVDs available for purchase
  - Dystonia Wallpaper- Screen-savers created by Joel Johnson, TV Productionist.
  - New ST brochure accompanies NEW T-Shirts Dystonia-ST
  - C4D chosen as a judge of [BOTOX DREAMS CAMPAIGN](#)
  - C4D joins the [Justice for All Campaign](#) to help revamp the ADA Civil Rights Amendments Act. The Act passes in US Congress in June. C4D is the only movement disorder non-profit within this highly recognized coalition.
  - [www.healthdigestnews.com](#) covers the story of dystonia
  - Dystonia T-shirts are created by Jim Flanders and sold to increase awareness ( 350 )
  - Medscape blogs renewed at <http://blogs.medscape.com>
- **2009 Media**
  - Journal of Neuroscience Nursing,
  - Nursing Spectrum x 2,
  - Intelistaff-MSN Network Newsletter
  - [www.neurologynow.com](#),
  - [www.facebook.com](#),
  - BI Connections x 2,
  - Swiss Dystonia Newsletter
  - 2008 New York Times Tribute to Nurses Award,
  - CNN Hero Nomination,
  - Self Magazine Submission,
  - Redbook Nomination,
  - [www.Medscape.com](#)
  - EHealthcare
  - Nurse Ezine
  - Exceptional Nurse Newsletter,
  - Disability and Nurses,

- [Mentor Biologics Corp](#) Newsletter x 2,
- Legal Press Releases re. Civil Rights, ADA Act
- <http://twitter.com/care4dystonia>
- <http://wefollow.com/tag/dystonia>
- TWIBES Online
- C4D with [NSTA](#) present at the Am. PT Ass. Baltimore, MD
- I'm Moving Two book is issued to over 300 needy patients- out of pocket costs.
- Magnets, Brochures remain free for distribution.
- Membership on the Wego Dystonia Ed Forum closes in on 285 !
- Updated C4D Web site is re-launched in Sept 2009.
- Nursing with a Movement Disorder noted in 4 publications including [www.healthdigestnews.com](http://www.healthdigestnews.com), [www.nursingtogether.com](http://www.nursingtogether.com) and [www.rnjournal.com](http://www.rnjournal.com)
- Partnership with Affinity Labs formulated with attention focused on dystonia awareness x 3 months
- [www.medscape.com/nurse](http://www.medscape.com/nurse) blogs continue.
- Partnership with the NEW American Dystonia Society is formulated by Nov 2009.

## 2010 C4D Initiatives

- New C4D gear are developed : key chains, magnets, mouse pads, notebooks, etc.
- Video Entrance into [www.neurofilmfestival.com](http://www.neurofilmfestival.com). More news released at the ANN Meeting in June 2010 in Toronto Canada.
- Dystonia Chat Room Opens March 14 2010
- C4D Face book Fan Club ceased to prevent duplicative efforts within the chaotic dystonia community- Entering Social Media
- New Collaborative Initiative with [www.dystonia.us](http://www.dystonia.us) begins in March 2010 on an ongoing basis..
- Teleconferences begin with the ADS, ST Zone, D-I International Yahoo moderators
- By April [Wego Health Dystonia Ed Forum](#) becomes the most active Forum with 350 members.
- C4D spreads the word about the possibility of Dr. Oz and Oprah teaming up on a story for 'rare illnesses ". Submit your story at [www.oprah.com](http://www.oprah.com). You may have a chance to be on Oprah for Season 25 !
- C4D Founder Beka is featured re. horsemanship and DBS by Medtronic, Inc.
- Merz USA issues Press Release featuring our Founder.
- Nancy Muller featured in Advances Radiology Tech Today.
- C4D together with the [NSTA](#) attend the American PT Ass. in Boston, MA in June !
- OPEN Letter to the Dystonia Community released by our Founder re. the status of research funding and community "clashing' issues.
- Nursing Spectrum does a repeat follow-up story on our Founder.
- Dec 2010 issue [www.abilitymagazine.com](http://www.abilitymagazine.com).
- Discover Nursing profile on [www.discovernursing.com](http://www.discovernursing.com) Sept newsletter.
- Johnson and Johnson Commercial Casting Call Finals for Nursing.
- Dystonia Trends 2010 Survey completed.
- An donation of ST Books is provided to [www.dystonia.us](http://www.dystonia.us).
- Newly refined web site launched November 2010.
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More to follow ! What will occur in 2011 ? Who Knows ??

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