



Dysautonomia Youth Network of America, Inc

“A Ray of Hope”

Membership Information

Please read the following information very carefully. Youth 18 and under should share this information with their parents. Youth 13 and under will need parental permission to join DYNA. We suggest everyone print this document for future reference.

What is DYNA:

DYNA is a 501 (c) (3) non profit organization dedicated to the cause of childhood dysautonomia conditions.

The purpose of DYNA is to facilitate change. Change in improving the lives of our DYNA members and their families; change in the community-at-large, to foster awareness and a better understanding of dysautonomia conditions; and change in the future, to encourage compassionate care, efficient diagnosis, and reliable treatment of childhood dysautonomia.

DYNA youth members are a pioneering group of young advocates that are afflicted with dysautonomia conditions. Instead of feeling sorry for themselves, they are taking action by spreading awareness and offering each other support via the Internet.

DYNA is a positive group of positive individuals.

What DYNA is not:

DYNA is not a place to hold pity parties.

DYNA is not a place to endorse alternative or controversial treatment options.

DYNA is not a place for individual self promotion.

DYNA is not a place for those who do not want to reach out to others.

DYNA is not the place for Internet dating relationships or teen popularity contests.

DYNA Mission Statement:

- To give hope for the future to those impacted by dysautonomia
- To provide positive support to young people who have dysautonomia
- To heighten awareness of these conditions and treatments
- To provide information on these conditions

Who can Join DYNA

Lifetime membership is offered to young people (up to age 21) who are medically diagnosed with a dysautonomia condition such as: Postural Orthostatic Tachycardia Syndrome (POTS), Neurally Mediated Hypotension (NMH), Neurocardiogenic Syncope (NCS), Vasovagal Syncope, Generalized Dysautonomia, Birth Dysautonomia, Non-Familial Dysautonomia, and/or Post-Viral Dysautonomia.

NOTES:

- We must have all of the required information to process your application for membership. Do not rush, take your time and be accurate.
- If you have any problems or questions, please feel free to contact us.
- Once you complete your application, if you do not hear back from us within a timely manner you should follow up with an email or phone call to confirm receipt of your registration information.
- DYNA is a PRIVATE group. Our membership list is to be kept confidential and is not for public release.
- We set very high standards for our members and do not support negative "clicks" forming within our membership. By joining DYNA you agree to rise above the petty aspects of gossip etc. that can bring in negative attitudes. You agree to honor our Youth Statute (below) and always be respectful and supportive of other members.
- Once your application is processed and you are approved for membership, if you wish to have your story posted on the DYNA web-site, please email it to us in a one-page Microsoft Word document. We welcome your stories and feel that they offer a great deal to others who view our site. We reserve the right to edit.
- After application you will be sent an email questionnaire that you must return to us. When we receive the questionnaire back from you we will contact you by phone to confirm/review your information. At that time you will be very casually interviewed for membership and we will give you a chance to address any questions you may have.
- When you apply for membership, you must list a home phone number. Your cell phone should be listed as an optional phone number. **One** call will be placed to you. If you are unavailable, it will be your responsibility to return the call to our main office.
- Once your application has been reviewed by our Directors and approval for membership has been issued - you will be given additional instructions on how to proceed.

DYNA Youth Statute:

- DYNA Members believe that having an illness does not mean that you have a weakness.
- DYNA Members are always respectful of differences and do not judge others.
- DYNA Members do not use profane language.
- DYNA Members are advocates for dysautonomia awareness.
- DYNA Members work towards group awareness and are not individual self-promoters.
- DYNA Members are always supportive of each other.
- DYNA Members endorse HOPE and maintain a positive attitude.

DYNA Mailing/Email Address:

DYNA Phone: 301-705-6995
Debra Dominelli, President
1301 Greengate Court
Waldorf, MD 20601

Debra L. Dominelli, President: ddominelli@dynakids.org

General Public DYNA Information e-mail Address: Info@dynakids.org

Unlike many organizations, we do not charge a membership fee. We realize that our families are going through a tremendously stressful situation and do not need the additional burden of sending a required membership fee for participation within our organization. However, we deeply appreciate all donations to our organization. Donations provide DYNA with the necessary funds to continue providing our support services, newsletter publication expenses, postage, operating expenses, activities such as our Summer Chill event, awareness promotions, etc. Without the kindness of others, DYNA would not exist.

Tax-deductible donations should be made out to:

DYNA, Inc.
1301 Greengate Court
Waldorf, MD 20601 Fax: 301-705-6995

DYNA "SUMMER CHILL":

DYNA holds a **"DYNA Summer Chill"** event in July. This wonderful event is PRIVATE and open to registered DYNA Members ONLY. Information about the Summer Chill will be made accessible to you once your registration process is complete. We keep the location and

information about this event private for safety reasons. You may view pictures from previous events on this site.

HIGHLY RECOMMENDED SUPPORT MATERIAL:

DYNA VIDEO:

The Summer Chill video of the DYNA "Goofy Slipper" lecture on dysautonomia is tremendously informative and helpful to families dealing with children impacted with dysautonomia. This information can help your school systems and other family members understand your condition. To order a DVD of this lecture please refer to our main web site page.

**THE FAINTING PHENOMENON:
UNDERSTANDING WHY PEOPLE FAINT AND WHAT CAN BE DONE ABOUT IT**

By: Blair P. Grubb, MD, Carole McMann, MPH, ISBN#: 0-87993-491-3
An excellent resource for families and physicians of individuals with POTS, NCS, and all dysautonomia conditions. To order please refer to our main web site page.