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THE HINGE
EDNF Monthly Update

APRIL 2007

First Anniversary Issue

Would you believe *The Hinge* debuted one full year ago?! Your interest, readership and contributions have made *The Hinge* the most popular new program at EDNF; I am so proud of this new service which allows us to keep you posted about what is happening with the Foundation and our busy membership.

Thank you all for allowing me this opportunity to increase our outreach and knowledge about EDNF and awareness of EDS. We continue to grow and expand and to carry our message to a wider and wider community, and with your help, we can reach so many more. It has been my pleasure to watch this growth and I am grateful for the chance to make our voices heard.

Happy Anniversary!

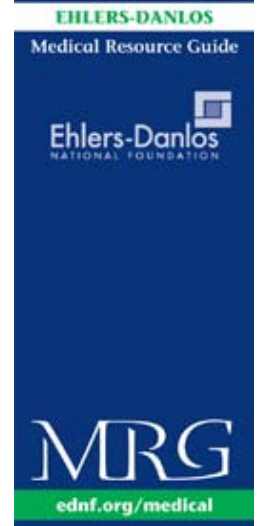
COMMUNICATION ⚡ COMMUNICATION ⚡ COMMUNICATION

EDNF Announces New “Medical Resource Guide”

EDNF is proud to announce a major revision of the *Ehlers-Danlos Medical Resource Guide*. This release is completely reworked, from a new design to updated information. It guides the Health Care Professional through an introduction to EDS and the EDNF website.

This is the latest step in the on-going mission of your EDNF: creating resources for those affected by Ehlers-Danlos Syndrome. The *EDMRG* is particularly important in this year of “Educating Our Doctors”—and by releasing the *EDMRG* during “May EDS Awareness Month,” particular attention is focused on our efforts to find new ways of distributing accurate information.

The *EDMRG* will be available May 15 at SHOP.EDNF.ORG. Watch for future *Medical Resource Guides* detailed for medical specialties, such as *Dentistry MRG* (scheduled for June) and *Ophthalmology MRG* (later this year); quite a few more are being planned for the years ahead.

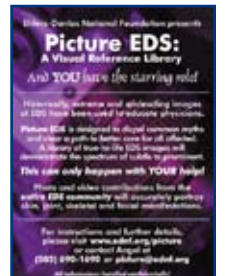


Loose Connections

Our June edition of *Loose Connections* will include one copy of the new *Ehlers-Danlos Medical Resource Guide*. If you would like *Loose Connections* delivered to your home, on real paper and with all the goodies it sometimes contains, simply upgrade to a regular membership by contacting MEMBERSHIP@EDNF.ORG.

“Picture EDS” Project is underway!

Historically, extreme images have been used to educate doctors and lay people about EDS. The goal of this project is to compile a visual library of true-life images that demonstrate the complete spectrum of subtle to prominent. This project needs *your* input! For more information, please [CLICK HERE](#). Please contact: PICTURE@EDNF.ORG with any questions.



May Awareness Art Display

EDNF Kids & Teens will be hosting a traveling display in four locations across the country. If you or your local group would be interested in participating, please contact MICHELEDARWIN@MAC.COM. We will be accepting entries for the Second Annual Art Contest through April 30, so it is not too late to send in your entries!



Teens In Action!

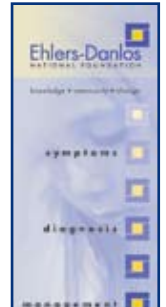
Firstgiving.com fundraising pages are a terrific way to raise money for EDNF and tell your story at the same time. Take a look at what two of our teenagers have done for EDNF with their efforts: WWW.FIRSTGIVING.COM/EDSDONATION and WWW.FIRSTGIVING.COM/NIKKIDARWIN. Feel free to pass on their websites to your friends and family and let these teens encourage ALL OF US to get out there and make a difference!

Website Update

To our members: as you will have noticed, there are changes happening with our website. We had hoped to make many of the changes and upgrades necessary invisibly and without too much disruption but things do not always go as we hope and plan. To read more about our changes, our experiences, and what we have to look forward to on the website, [CLICK HERE](#).

Patient Brochure Available for Download

The patient brochure developed for EDS Awareness Month in 2006 is now available on the website for download. A benefit of the new website server allowed for larger files and so we are reaping some of the rewards for the changeover. [CLICK HERE](#) to download the patient brochure.



Society of Investigative Dermatology

EDNF will be attending and distributing information at the 2007 meeting of the Society of Investigative Dermatology in Los Angeles the weekend of May 12. We hope to highlight the need for increased awareness of associated dermatology issues with EDS patients. A schedule of upcoming medical conferences will be posted on the website soon. Consider doing the same at a conference near you.

Kudos as Local Groups Create May Awareness Excitement

May is EDS and EDNF Awareness Month. Some of our local groups are building excitement.

Local Group of Greater San Diego - Taxi Tops

Yellow Cab of San Diego is donating ten Taxi Tops Ads from April 18 through the month of May. In addition to the general awareness this provides, it will be especially noticed the week of April 19 when doctors throughout the nation will be attending the American College of Physicians Internal Medicine Conference 2007.

Are You Hypermobile and in Pain?
You may have **Ehlers-Danlos Syndrome**, a connective tissue disorder.
Learn more at www.EDNF.org

EDS Advocates of Northern California

EDS Advocates of Northern California is participating in the local Marin County Human Race this year as part of their May Awareness campaign to raise funds for EDNF! They will have an informational booth with EDS/EDNF material to hand out and talk to people about, while also participating as fundraising teams to raise as much money as possible for EDNF.

Piedmont Triad Branch of EDNF also participated in Human Race

North Carolina's race/walk/wheel took place in March. This group has participated in the fundraising event for a number of years.

Western New York Branch of EDNF Adds Posters to the Mix

The group has developed a new poster for ERs and will be placing these in hospital ERs as well as putting up the [SPORTS AND COACHES POSTER](#) developed last year in schools throughout their area.

Read a Good Book Lately?

With the realization of the time EDSers require for healing and recovery, the idea for a place to discuss books and or books on tap came to mind. Reading *Moloka'i* by Alan Brennert, a book which resonates with those of us struggling with that which life presents us, provided the final impetus for the addition of a place for such sharing. It is located on the message boards in the support section. Join in to share books, talk about them, and even arrange for possible book club chats on our website [MESSAGE BOARDS](#).

FirstGiving

Want to know a quick and easy and ongoing way that YOU (and anyone you know) CAN HELP support the programs of the EDNF without having to do much more than make a few clicks on your computer? Go to [HTTP://FIRSTGIVING.COM/EDNF](http://FIRSTGIVING.COM/EDNF) and click the “Get Started” button.

Don't Forget Mother's Day is May 13th

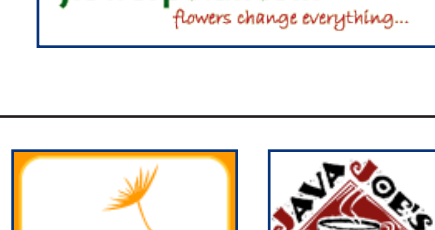
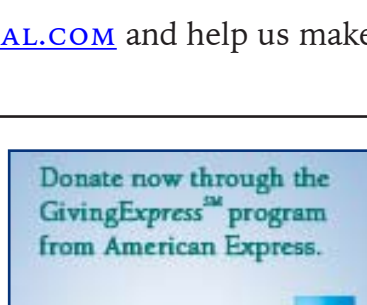
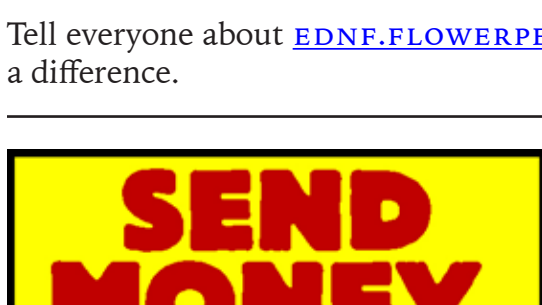
[HTTP://EDNF.FLOWERPETAL.COM](http://EDNF.FLOWERPETAL.COM)

Now when you order flowers at EDNF.FLOWERPETAL.COM, 12% of each purchase goes to EDNF. That's \$6 for a \$50 purchase and \$12 for \$100.

There are no additional fees for delivery, even same day delivery! And you can save up to \$10.95 compared to other on-line florists. So every purchase puts a smile on many faces—including yours!

Powered by:

Tell everyone about EDNF.FLOWERPETAL.COM and help us make a difference.



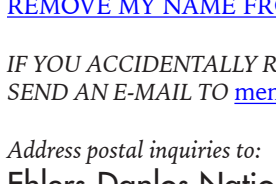
Please send your comments as well as possible items for future Hinges to barbara.edsrc@charter.net. Items must be submitted for inclusion by the 10th of the month.

[REMOVE MY NAME FROM ALL FUTURE E-MAIL CORRESPONDENCE](#)

IF YOU ACCIDENTALLY REMOVE YOUR NAME FROM FUTURE MAILINGS, SEND AN E-MAIL TO membership@ednf.org WITH “RESUBSCRIBE” IN THE SUBJECT LINE.

Address postal inquiries to:
Ehlers-Danlos National Foundation
3200 Wilshire Boulevard South Tower, Suite 1601
Los Angeles, CA 90010

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