Welcome from the President

Dear Friends,

We have undertaken a massive membership renewal drive with new technology that allows you to log in and manage your Genetic Alliance account. Advocacy organizations can update their listings in Disease InfoSearch, and everyone can register for events! With the enormous increase in services, resources and communications we offer, we are thrilled that this will keep you connected and make it easy for you and us!

It is the season of giving—beginning with our ‘Thanksgiving’ for you! Advocacy organizations, healthcare providers, researchers, corporations, policymakers, government agencies all—you contribute to the richness of our community and we are grateful for all you offer. We ask you in this season of giving to support this robust network in which we all thrive. Please contribute, donate, or pay a voluntary dues to us this year—we have not asked in years, and feel that now we are ready to ramp up with more services that will allow you to succeed. Help us help you! [Donate here](#).

Best wishes in the Holiday Season,

Sharon Terry

---

Spotlight: Membership Drive

---
Disease InfoSearch gets thousands of hits a week and helps newly diagnosed individuals, their families and healthcare professionals find you—member organizations.

If you are an advocacy organization leader, you will receive a call from us in the next few months! We want you to be aware of all that we offer, and to encourage you to update your listing in Disease InfoSearch. Disease InfoSearch gets thousands of hits a week and helps newly diagnosed individuals, their families and healthcare professionals find you—member organizations. Genetic Alliance believes that advocacy organizations are the best source of information on genetic conditions. Not only are you aware of the latest research, treatments and resources, but you also drive them!

And here is the special incentive! If you update your Disease InfoSearch listing during the Membership Drive you will receive a $25 discount off a full registration for the annual conference (July 27-29, 2007).

Thanks to those who have already updated their information. You can make sure your organization’s information is up-to-date on our website by signing in at www.geneticalliance.org/signin. If you have any questions about signing in please contact membership@geneticalliance.org.

Capitol Corner

Genetic Testing Policy

Genetic Alliance hosted a dynamic webinar on the Food and Drug Administration’s (FDA) two draft guidances on genetic testing on November 6 with more than 150 people in attendance from stakeholder groups. National genetic testing experts from government, industry, policy, and the consumer communities discussed the guidances on analyte specific reagents (ASRs) and in vitro diagnostic multivariate index assays (IVDMIAAs) during the two-hour session. We encourage participants to weigh in on the guidances before the comment period expires on March 5.

All members of the Genetic Alliance community are encouraged to learn about the FDA draft guidances and make their voices heard on this important issue. Informative slides presented during the webinar are available online along with copies of the draft guidances.

Genetic Alliance will be drafting comments and inviting all interested parties to sign on or craft their own comments and submit them directly to the FDA.
Genetic Alliance continues to advocate for a genetics specialty under the Clinical Laboratory Improvement Amendments (CLIA). Most recently, the Genetic Alliance community rallied together to endorse a letter to key decision-makers at the U.S. Department of Health and Human Services (HHS) requesting action to create the specialty. View a copy of the letter and list of signatories.

Leadership with the National Institutes of Health

As the leader of the genetics consumer community, Genetic Alliance is often called upon for testimony and public comment. This month, Genetic Alliance drafted responses to two policies proposed by the National Institutes of Health (NIH) and testified before one of their advisory bodies.

In response to a request for information (RFI), Genetic Alliance submitted comments to NIH on their Roadmap II initiatives, which lay out the direction for innovative and novel disease research. The comments were submitted on November 17 with Genetic Alliance community signatories.

Genetic Alliance has also prepared a response to another NIH RFI on the data-sharing policy genome-wide association studies (GWAS). Genetic Alliance members signed on in support of our comments. View Genetic Alliance’s comments.

GA Out & About

GA in Spain
Genetic Alliance participated in the International Conference for Rare Disorders (ICORD) and the European Platform for Patients, Organizations, Science and Industry (EPPOSI) in Madrid, Spain in October 2006. Both meetings brought together representatives from key stakeholder groups, including patients, regulators, charities, academics, clinical communities, industry and providers from around the world. Dialogue focused on the value of an international exchange of information and emerging issues in patient therapies. Genetic Alliance Vice President, Lisa Wise, facilitated a discussion on collaboration and the international health care agenda.

We commend our colleagues from around the world for their efforts and would like to offer our support in their work to increase the capacity of their patient communities.

GA at the American Public Health Association Meeting
James O’Leary, program manager of Genetic Alliance, presented a poster on our Community Centered Family Health History project to more than 13,000 public health
Managers, policymakers, and community health workers at the American Public Health Association meeting—a great honor for James and Genetic Alliance! James also participated in education sessions on community participatory research, health education, and genetics and disease.

Meet New Staff: Natasha Bonhomme

Natasha Bonhomme joined Genetic Alliance in October to work on the family health history initiative, as well as other projects relating to membership and public policy. She has a strong background in research and grant writing and implementation.

A graduate of Boston College, Natasha earned a Bachelor of Arts in Psychology with a pre-medical concentration. Prior to joining Genetic Alliance, Natasha worked on issues relating to education and health policy as a Project Associate at the Georgetown Center on Health and Education in Washington, DC. She also has experience in community health education and initiative development. Natasha was born and raised in the Washington DC metropolitan area.

Upcoming Teleconference Schedule:

Creating your Organization’s Brochure: Literacy, levels and look
Wednesday, December 6 at 12 noon EST (Call-in or in-person)
Learn how to create a brochure that people will want to pick up and read!
Paula Raimondo of the Health Sciences Library at the University of Maryland and Melissa Allen Design will provide pointers on developing attractive, readable brochures at the right level for your audience.

Money Matters: Fundraising for Rare Diseases
Wednesday, January 10th, 2007 12:00pm EST (Call-in or in-person)
With special guest presenters:
Audrey Gordon Progeria Research Foundation
Jennifer Thornton A-T Children’s Project
Jonathan Martin Marfan Syndrome Foundation (invited)

To register for one or more of these exciting sessions, click here.

Celebrating Our Leaders: Bronwyn Gray
Miss the Leadership Exhibit at Genetic Alliance's 20th Anniversary Gala in September? We will be honoring leaders from the exhibit throughout the year. Click to see full image.

Bronwyn Gray, New Zealand Organisation for Rare Disorders

When Bronwyn Gray's daughter Lisa was diagnosed with Lymphangioleiomyomatosis, Bronwyn had a choice--accept their fate, or fight. She chose to fight and brought together families, researchers, and specialists worldwide to special symposia for the disease. Her drive and commitment have shifted the boundary of knowledge for this disease.

G.Advocacy is a monthly electronic newsletter distributed by Genetic Alliance. If you know someone who might also like to receive the newsletter, please feel free to forward him/her this message.

If you received this from a friend and would like to subscribe, sign up here.

Credits
Editor: Karen White
Contributors: Lisa Wise, Orkideh Malkoc and Sharon Terry
Webpage: Kim Puchir

Copyright © 2004-2006 Genetic Alliance, Inc. All rights reserved. ISSN 1933-4176