

NHF NATIONAL YOUTH LEADERSHIP INSTITUTE
October 27-29, 2005
San Diego, California

The National Hemophilia Foundation is pleased to hold its second annual *NHF National Youth Leadership Institute (NYLI)* —a program for young adults. We encourage you all to apply and be part of this special event.

About the NHF National Youth Leadership Institute

The NHF National Youth Leadership Institute (NYLI) has been created to encourage young adult participation and foster the development of future leaders of the bleeding disorders community. The NYLI will be a 3-day meeting and take place in conjunction with NHF's 57th Annual Meeting in San Diego, California on October 27-29, 2005.

NYLI will serve as a forum to introduce young adults to the broader bleeding disorders community, learn about important issues and meet people with common interests. The curriculum will consist of specially designed educational sessions for young adults with leadership potential focusing on leadership skills, teambuilding activities and problem-solving techniques. Additionally, the attendees will have an opportunity to select and attend NHF Annual Meeting's adult sessions and participate in a fun and educational field trip.

Who Can Apply?

Chapters and local hemophilia associations are invited to send **up to two young adult delegates**. Delegates could be diverse young men and women *affected by bleeding disorders ages 18 years and older, siblings included, who exhibit above average leadership potential. See Appendix A. Note that youth that are younger than 18 years of age are invited to come as long as they attend the meeting and room with a parent/guardian. The parent/guardian must also agree to provide any additional supervision as needed.

**Note that young adult delegates affected by bleeding disorders could include youth with a bleeding disorder, their nonaffected siblings, carriers or youth whose parents or relatives or close friends have bleeding disorders.*

Who Else Can Participate?

Chapters and local hemophilia associations are encouraged to nominate one mentor. The mentor could be an adult volunteering in a chapter, association and/or hemophilia treatment center and should meet the mentoring criteria in Appendix B. This person would agree to serve as a role model for the young adult delegate and provide guidance and support. Most importantly, the mentor must agree to help the young adult carry out the skills learned during the NYLI training and implement prevention activities in the local area.

The mentor does not need to travel to the Annual Meeting but the mentor should make time available (approximately 5 hours per month) after the NYLI training to provide direction and feedback to the young adult. [Note that there may be funds available to mentors that are willing to travel to the Annual Meeting. If you are interested in sending a mentor, please indicate this on the attached application.]

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Eligibility and Selection Process

Each chapter and local hemophilia association is invited to nominate up to two young adult delegates from their organization to attend the NHF National Youth Leadership Institute. From among the pool of candidates, NHF will select the top young adult candidates exhibiting above average leadership potential and willingness to become active leaders in their local bleeding disorders community of residence and/or camp. NHF will develop a strategy and action plan for the young adult to implement a prevention program at the chapter/association or camp.

Applications will be reviewed and evaluated by a volunteer review team which includes one representative each from an HTC and chapter, one NHF volunteer consumer, and one camp director. Criteria will include leadership ability, extracurricular and community service, recommendations, and application essay. Applications will be reviewed and awarded based on criteria described above and funding available. The winners will be announced during the month of August.

Scholarship Funding

The scholarship will include all paid expenses for the young adult delegate (e.g., travel, hotel, meals, etc.).

Application Requirements

Please complete the requirements below.

For young adult delegate to complete:

- 1) Application forms for young adult delegate
- 2) Character recommendation
- 3) Essay

For chapter/association staff to complete:

- 1) Application forms for chapter/association staff
- 2) Chapter/association staff recommendation

Deadline

All applications must be postmarked by July 29, 2005. Please forward your completed application (including all attachments) to the following address:

Lauren Daitch, MPH
Education Manager
National Hemophilia Foundation
116 West 32nd Street, 11th Floor
New York, New York 10001
Phone: 1-800-42-HANDI (ext. 3756)
Fax: (212) 328-3799
Email: Ldaitch@hemophilia.org

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APPLICATION: FOR YOUNG ADULT DELEGATE TO COMPLETE

Please print or type in the following information. This form along with your essay (see attached) and a statement of recommendation (see attached) must be postmarked no later than July 29, 2005. Please send to Lauren Daitch, National Hemophilia Foundation, 116 West 32nd Street, 11th Floor, New York, New York 10001.

Name of Applicant _____

Age _____

Home Address _____

Home Telephone () _____

Work or College Dorm Telephone if Applicable () _____

E-mail _____

Best Time to Contact _____ A.M./P.M.

Affiliation to Hemophilia/Bleeding Disorders Community (i.e. Do you, a family member, or friend have a bleeding disorder)

My Local Chapter/Association is _____

My Hemophilia Treatment Center is _____

Do you have any personal or business relationship, or circumstance that you believe could contribute to a conflict of interest as defined in the National Hemophilia Foundation's Volunteer Code of Conduct (See Appendix C)

Current School _____

Have you been accepted to a college or technical school? _____ Where? _____

Please complete if applicant is younger than 18 years of age.

Name of parent/guardian _____

As a parent/guardian, I agree to attend and room with my son/daughter at the NHF Annual Meeting and will be responsible for providing any supervision as needed.

Signature _____

APPLICATION: FOR YOUNG ADULT DELEGATE TO COMPLETE (Continued)

Please list all activities that you have been involved in for the last four years. Please include dates if possible. You may use additional pages if necessary.

SCHOOL ORGANIZATIONS

ATHLETICS

AWARDS, HONORS, ACHIEVEMENTS

VOLUNTEER WORK/COMMUNITY SERVICE (Please also include work pertaining to bleeding disorders)

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CHARACTER RECOMMENDATION

Note to young adult applicant: Please fill out the first two lines of this form and give it to a teacher or personal reference (not a relative) that can answer the following questions. DUE: Postmark by July 29, 2005.

Name of Applicant: _____

Address of Applicant: _____

What is your relationship to the above applicant? _____

Name of reference: _____

Address of reference: _____

Phone Number/E-Mail Address of reference: _____

How long have you been acquainted with this applicant? _____

What are this applicant's most significant talents? _____

Please describe in detail why you are recommending this person for the NHF National Youth Leadership Institute. (You may attach a separate page if you choose.)

Signature of reference _____

**Please mail to: The National Hemophilia Foundation, 116 West 32nd Street, 11th Floor,
New York, New York 10001
Attention: Lauren Daitch**

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ESSAY: FOR YOUNG ADULT DELEGATE TO COMPLETE

Please respond to the following essay question in 250 words or less. Please print or type. You may use the space below or a separate sheet of paper. DUE: Postmark by July 29, 2005.

Please discuss a past leadership experience and explain how you can use this experience to benefit the bleeding disorders community.

Please mail to: The National Hemophilia Foundation, 116 West 32nd Street, 11th Floor, New York, New York 10001, Attention: Lauren Daitch

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APPLICATION: CHAPTER/ASSOCIATION STAFF TO COMPLETE

Please Print or Type in the following information. This form along with the chapter/association staff recommendation sheet must be postmarked no later than July 29, 2005. Please send to Lauren Daitch, National Hemophilia Foundation, 116 West 32nd Street, 11th Floor, New York, New York 10001.

Name: _____

Title: _____

Organization: _____

Address: _____

Telephone: () _____

E-mail: _____

Best Time to Contact: _____ A.M./P.M.

Name of young adult delegate(s) you are recommending:

1) _____

2) _____

Name of mentor you are recommending:

Telephone Number of Mentor: () _____

E-mail of Mentor: _____

Will the mentor be traveling to the Annual Meeting?

Will the mentor require funding?

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RECOMMENDATION: CHAPTER/ASSOCIATION STAFF TO COMPLETE

Please Print or Type in the following information. Note that you may attach a separate page if you choose. Please send to Lauren Daitch, National Hemophilia Foundation, 116 West 32nd Street , 11th Floor, New York, New York 10001. DUE: Postmark by July 29, 2005.

Name of Applicant: _____

Please describe in detail why you are recommending this person for the NHF National Youth Leadership Institute.

Please list the young adult delegate’s responsibilities within your organization.

Please list the young adult delegate’s accomplishments while volunteering within your organization.

Signature of reference _____

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APPENDIX A: Young Adult Delegate Job Description

Goal of NHF National Youth Leadership Institute

The goal is to encourage young adult participation in National Hemophilia Foundation and chapter/association activities, enhance the knowledge and understanding of preventive practices among young people and foster the development of future leaders of the bleeding disorders community.

Description of Role

Young Adult Delegates will serve as peer educators and help educate young people about bleeding disorders and motivate them to get involved in youth programs across the country. After the NHF National Youth Leadership Institute training, young adult delegates will be equipped with enhanced leadership qualities, problem-solving skills and presentation tactics for promoting key prevention education messages to the young adult consumer population in their local areas.

Eligibility for Young Adult Delegate

The young adult delegate must be a young man or woman ages 18 and older affected by a bleeding disorder (could include youth with a bleeding disorder, their nonaffected siblings, carriers or youth whose parents, relatives or close friends have bleeding disorders).

Skills Desired

- Demonstrated leadership skills (e.g. sports, school organizations, extracurricular activities)
- Has been involved in volunteer activities (including ones pertaining to bleeding disorders)
- Has excellent follow-through capabilities and willingness to stay focused on the specific activity and remain committed beyond the training phase
- Demonstrated outstanding academic achievements
- Ability or willingness to present in front of small and large groups
- Strong written communication skills
- Demonstrated ability to work in a team environment
- Respect for, awareness of, and adherence to the principles and concepts taught at the NHF National Youth Leadership Institute training
- Ability to foster and maintain effective relationships with the bleeding disorders community—young adults, consumers, summer camp personnel, HTC representatives, and chapter/association staff

Availability

All young adult delegates should be able to dedicate five hours a month to peer education activities, and must make a one-year time commitment

Responsibilities

- Give a small or large group presentation to young people affected by bleeding disorders at a chapter/association event and/or summer camp
- Attend and participate in national, local chapter/association and summer camp meetings
- Help NHF and the chapter/association plan education opportunities in the local area
- Help NHF and the chapter/association understand issues particular to young adults
- Report back progress on an ongoing basis to NHF representatives
- Help prepare articles for NHF and chapter/association publications and/or Web site

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APPENDIX B: Mentor Job Description

Goal of NHF National Youth Leadership Institute

The goal is to encourage young adult participation in National Hemophilia Foundation and chapter/association activities, enhance the knowledge and understanding of preventive practices among young people and foster the development of future leaders of the bleeding disorders community.

Description of Role

This person would agree to serve as a role model for the young adult delegate and provide guidance and support. After the NHF National Youth Leadership Institute training, mentors will help the young adult delegate promote prevention messages to the young adult consumer population in their local areas.

Eligibility for Young Adult Delegate

The mentor must be an adult volunteering in chapters, associations or hemophilia treatment centers.

Skills Desired

- A history of outstanding performance while working within your organization
- Recognition as an outstanding mentor and maintains positive relations with staff, young adults and peers
- Possession of strong interpersonal and collaborative skills
- Ability to discuss instructional materials and present ideas in a clear and concise manner
- Promote teamwork by sharing knowledge, cooperating with others, participating in meetings
- Supervise, train and empower young adult delegate to become a leader within his/her community
- Ability to foster and maintain effective relationships with the bleeding disorders community—young adults, consumers, summer camp personnel, HTC representatives and chapter/association staff

Availability

All mentors should be able to dedicate five hours a month to peer education activities, and must make a one-year time commitment

Responsibilities

After the Annual Meeting, the mentor should help provide opportunities within the local community for the young adult to:

- Give a small or large group presentation to young people affected by bleeding disorders at a chapter/association event and/or summer camp
- Attend and participate in national and local chapter/association meetings
- Help prepare articles for NHF and chapter/association publications and Web site

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APPENDIX C: NHF Volunteer Code of Conduct

NATIONAL HEMOPHILIA FOUNDATION VOLUNTEER CODE OF CONDUCT

This Code of Conduct is designed to assist each volunteer in abiding by the mission, philosophy and policies of the National Hemophilia Foundation (NHF). Volunteers represent NHF and set examples through their ethical conduct and professionalism. In return, volunteers will be treated with respect and openness, be assigned responsibilities appropriate to their level of competence, and have access to leadership development opportunities.

Failure to follow this Volunteer Code of Conduct may result in suspension from volunteer duties and/or termination of the volunteer relationship with the National Hemophilia Foundation.

As an NHF Volunteer, I pledge that:

RESPECT FOR OTHERS

- I will treat staff, other volunteers, and members of the community with dignity, care and respect. I will be sensitive to and educate myself about individual and group differences, I will honor all persons rights to self-determination and agree to support people in making their own personal choices.
- I will comply with NHF's policies and understand that NHF neither practices nor tolerates discrimination or harassment against any individual on the ground of race, color, religion, creed, gender, national origin, nationality or ancestry, citizenship, age, legally defined disability, genetic predisposition, or carrier status, marital or familial status, sexual or affectional orientation, veteran status or eligibility for service in the armed forces or any other characteristic protected by law.
- I will dress and act at all times in a manner which will be appropriate to my assigned responsibilities.
- I will not use profane, vulgar or obscene language, gesture, behavior or any other sign of disrespect towards anyone while participating in NHF activities.
- I will respect the property and material of NHF, hotels and other facilities used by NHF for its activities. I understand that I am responsible for safekeeping of NHF property as well as my own personal property.
- I agree to maintain respectful and professional relationship boundaries during the course of my volunteer work and agree to speak with my supervisor should any relationship develop that makes it difficult to remain objective and fulfill my volunteer obligations.

ACT PROFESSIONALLY AND TAKE RESPONSIBILITY FOR MY ACTIONS

- I will provide for the general welfare, health, and safety of any NHF participant in my charge during the course of my assigned duties.
- I will report any emergencies to the appropriate authorities after first taking immediate action to ensure the health and safety of the participants.
- I understand that being under the influence of alcohol or drugs may interfere with my ability to deliver service. I agree not to perform my volunteer duties while under the influence of drugs or alcohol, not to provide anyone with illegal substances or encourage their use, and not to participate with anyone in alcohol consumption to the point where my effectiveness is impaired. I will comply with all federal, state and local laws

regarding alcohol and drugs. I understand that many state laws prohibit alcohol consumption by persons less than 21 years of age.

- I will use tobacco products only where legally permitted and refrain from the use of tobacco products while conducting or assisting in any NHF program or in other group situations that may glamorize such use in the eyes of young people.
- I understand that violence is not tolerated by NHF and I will use nonviolent techniques to resolve any conflicts that arise and seek assistance when needed. I understand that fighting, weapons of any kind or firearms are prohibited at any NHF functions.
- I will immediately report any unsafe behavior or unsafe condition to an NHF supervisor or Volunteer Coordinator.
- I will not engage in any type of inappropriate behavior, sexual activity, and/or verbal or physical abuse with staff, other volunteers, or the general community at NHF sponsored activities.

CONFIDENTIALITY

- I agree to consider information pertaining to medical conditions, family relations, phone numbers and addresses, sexual orientation, and other facts of a highly personal nature as confidential. I further understand that I may not disclose this information to any person who is not authorized by NHF to have access to such information without the specific permission of the individual concerned.

ENSURE A POSITIVE EXPERIENCE

- I will update myself on the responsibilities of my role and new information, attend scheduled meetings, and take advantage of opportunities to learn and share information. I agree to ask questions and get answers and follow through and complete all accepted tasks.
- I agree to participate in supervision or guidance by the NHF designated Volunteer Coordinator according to my assigned program. I understand that supervision guarantees accountability for the performance of assigned responsibilities, provides an opportunity for feedback and guidance, and assistance and support in my role as a volunteer.
- I agree to maintain the limits I set for myself with respect to the emotional and physical resources I am willing to provide to NHF.
- I understand that my training and education may limit my ability to serve constituents and recognize the need to ask for assistance or referral from my Volunteer Coordinator when appropriate.

CONFLICT OF INTEREST

- I commit to my understanding and upholding of NHF'S Conflict of Interest policy. I agree to discuss any potential conflict with my supervisor and commit to being truthful in all matters to do with my volunteer relationship with NHF.
- I agree to put organizational goals before my personal goals. I will think broadly and focus on the best interests of individuals with bleeding disorders.

I hereby certify that I have reviewed, understood and agreed to this Code of Conduct.

Print Name of Volunteer

NHF Program or Assignment

Signature of Volunteer

Date