

Guidelines for Growing Brochures - An Action Plan for Parents of Children with Bleeding Disorders

Authors: Chad Feay; Jennifer Crawford, MPH; Gretchen Simmons, MPH, MCHES; Ayana Woods, MPH

Organizations: National Hemophilia Foundation (NHF) and Centers for Disease Control and Prevention (CDC)

OBJECTIVES

To create consumer friendly brochures based on the transition guidelines recommended by NHF's Medical and Scientific Advisory Council (MASAC).

BACKGROUND & METHODS

The National Hemophilia Foundation (NHF) recognizes that youth with bleeding disorders face a number of difficult and ongoing medical challenges as they mature and learn to manage their health. Hemophilia treatment center (HTCs) professionals have developed transition guidelines that were endorsed by NHF's Medical and Scientific Advisory Council (MASAC). These guidelines help HTC providers monitor a child's and family's progress, and prompt parents to consider their needs in several areas: social support, health and lifestyle, educational planning, self-advocacy and self-esteem, and ways to understand and make the best use of the healthcare system.

In its current checklist format, the transitions document is extremely useful to providers, but less so to consumers. As part of its *Steps for Living* education program, NHF created task forces consisting of medical providers, NHF chapter personnel, and member of the bleeding disorders community. In partnership with the Centers for Disease Control and Prevention (CDC) and these task forces, NHF revised and translated the document to make it consumer-friendly and separated the information into five age-specific brochures titled *Guidelines for Growing*. Each brochure covers transition information for specific age groups beginning with infants (Birth-4), children (5-8), older children (9-12), teens (13-15), and young adults (16-18), and focuses on important milestones of a youth's development as they relate to his or her bleeding disorder. The brochures have been reviewed by HTC personnel, NHF chapter teams, and the CDC.



RESULTS

In the three months since distribution began (March – May 2012) over 10,500 brochures have been distributed to 141 HTCs and 50 NHF chapters.

While a formal evaluation is pending, HTCs and NHF chapters have reported positive and favorable responses from their patients and members as they distribute *Guidelines for Growing* in various settings such as comprehensive clinics and educational meetings. Initial survey results (N=20) of the *Guidelines for Growing* brochures indicate:

- 74% learned new information
- 100% found the information relevant
- 90% felt the information was easy to understand
- 100% (of parents) viewed the brochures as a helpful tool to use with their children
- 95% said the brochures are helpful to use with healthcare providers

Guidelines for Growing are available in print and PDF in both English and Spanish and are available by contacting NHF's Manager of Education or by downloading from NHF's *Steps For Living* Web site or the CDC Web site.

RESPONSES

"*Guidelines for Growing* brochures are a great educational asset for the bleeding disorder community. The *G4G* series presents information from the MASAC transition guidelines in a practical and easy to understand format for families. These brochures help support the education we provide to families to help their children grow and develop. The age-specific format of the series allows for a gradual learning and application of skills and behaviors that teens with bleeding disorders will need as they transition into adulthood."

Deniece Chevannes, MPH, CHES
Hemophilia of Georgia

"The *Guidelines for Growing* brochures are a terrific addition to the materials we share with our members. Many young parents are hungry for knowledge after receiving a diagnosis and have told us how helpful these are in learning about what to expect not only at a young age but also as their child grows.

Here is a recent e-mail I received from a new member: 'Thank you so much Ms. Cowell for the packet. It is great. I have never received such great information regarding hemophilia. It will be so helpful for the future.'

Charlene Cowell
Hemophilia of North Carolina

"The [*Guidelines for Growing*] brochures are a great addition to our transition program and resource for our patients and their families.

We have received very positive comments such as: 'Thank you, this brochure offers informative suggestions and it is a "quick go-to" regarding resources, planning and helpful information regarding my toddler.' 'I'm new to hemophilia and I appreciate the information the brochure gives me.' 'I told my mom to read it so she will let me start taking care of things myself, stop controlling everything, and let me talk when I'm being asked questions.'

Tonya Hegwood, MSW, LCSW
Indiana Hemophilia and Thrombosis Center, Inc.



As a result of reading the *Guidelines for Growing* brochures, I am more knowledgeable about:

