

Initiative Objective: Provide Public Policy Advocacy on behalf of the bleeding disorder community.

Statements of Purpose:

What Success (Benefits) Will Look Like: Protecting and assuring the rights and interests of the bleeding disorder community. Improving the skills and empowering people to advocate on their behalf in the public arena.

What the Consequences Are for not Achieving: Constituencies will be hurt financially, access, insurance. People will be confused by the bombardment of information; GLHF may lose credibility—our responsibility for the voice of people.

Goals

1: Implement a workflow process for committee to utilize when addressing public policy issues on behalf of the bleeding disorders community by January 2006.

2: By July 2006, have completed research on a minimum of five (5) avenues to influence public policy that most closely align to the local (GLHF) bleeding disorders community in areas of: legislation, public policy, insurance, patient and consumer rights.

3: Annually provide bleeding community with detailed information on a minimum of 3-5 priority issues per year in 2007.

DETAILS

- Form Advocacy Committee by July 2005.

Goal 1: Implement a workflow process for committee to utilize when addressing public policy issues on behalf of the bleeding disorders community by January 2006.

Primary Tasks to Achieve Goal	Accountable:	Deadline:	Completed:
Contact other organizations to find out their processes so we may develop "Cookbook" plan in minimum timeframe. Research includes each of our target areas: - Legislation - Public policy - Insurance - Patient and Consumer Rights	Celene – Legislation David – Insurance Etc. - Public Policy - Patient and Consumer Rights	October 2006	
Develop & Document processes to use			
Monitor whether processes are working / effective			

Note:

- Be certain to factor in how to best leverage existing expertise/intellectual capital (i.e. David Linney)!

Goal 2: By July 2006, have completed research on a minimum of five (5) avenues to influence public policy that most closely align to the local (GLHF) bleeding disorders community in areas of: legislation, public policy, insurance, patient and consumer rights.

Primary Tasks to Achieve Goal	Accountable:	Deadline:	Completed:
Write PACT Grant			
Research how other Hemophilia chapter and other			
Investigate Washington Days			
Investigate feasibility & value of Lobbyist			

Goal 3: Annually provide bleeding community with detailed information on a minimum of 3-5 priority issues per year in 2007/08.

Primary Tasks to Achieve Goal	Accountable:	Deadline:	Completed:
Research Key Issue using developed best practice			
Conduct Analysis of Key Issue using developed best practice and document findings			
Report on Key issue (Communication via written, verbal, public awareness, lobbyist, etc.			