

An Interactive Guide to Building Lay Advocacy Groups

Assessing Your Needs

Name of organization		
-		
Name of condition		

u CHARACTERIZE THE CONDITION

Age of Onset	Early		•	•	•		•	•	Late
Systems Involvement	One		•	•	•	•	•		Many
Intensity	Episodic	•	•	•	•	•	•	•	Chronic
Availability of Treatment	Low	•	•	•	•	•	•	•	High
Effectiveness of Treatment	Low	•	•	•	•	•	•	•	High
Burden of Care (time/effort)	Low	•	•	•	•	•	•	•	High
Burden of Care (financial)	Low		•	•	•	•	•	•	High
Disabling Effect	Low		•	•	•	•	•	•	High
Life Threatening	No		•	•	•	•	•	•	Yes
Incidence/Prevalence	Rare		•	•	•		•	•	Common
Psychosocial Involvement	Low		•	•	•	•	•	•	High

Big dreams

In two years		
In five years		
In ten years		
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These worksheets were developed by Sharon F. Terry and are available in PDF format in the Genetic Alliance Interactive Guide to Building Lay Advocacy Groups (http://www.geneticalliance.org/InteractiveGuide/), published in 2004. These worksheets are made available under a Creative Commons license. More information is available at http://www.geneticalliance.org/InteractiveGuide/. You may make and share copies of these worksheets for noncommercial purposes without modifications and with this acknowledgement included in full.