

Us TOO's Guidelines and Your Us TOO Support Group Chapter

You have decided to commit your time and energy to starting your own Us TOO support group chapter. All of our groups commit to conducting a support group. Support groups, referred to as chapters by Us TOO are seen as independent in nature. Us TOO is not here to manage your group, we are here to facilitate your success. You will quickly find there are many people willing to help you create your chapter.

While no hard and fast rules exist for the size or format of your support group chapter, we do want you to benefit from our experience and understanding of what works and what pitfalls to avoid.

Using the basic information provided here and following a proven path, your support group chapter can get off to an excellent start. Your chapter will invariably take on its own character. Even as part of a larger global network of chapters with a similar focus, your chapter will have characteristics unique to your support group chapter alone.

Why Guidelines?

The world has changed and times have changed. Since 9/11 in particular the rules governing non-profit organizations have changes a great deal. Some of the structural guidelines and suggestions you find in this booklet are a reflection of these changes in our country since 2001.

Us TOO chapters are independent and we do not tightly monitor or try to manage each group. We do, however, ask each group to follow these guidelines and sign a chapter agreement.

These guidelines, created over the years by Us TOO's volunteer Board of Directors, are in place to help all of us maximize the power and effectiveness of the network. These guidelines provide standards to which we can all rise. We thank you in advance for thoroughly completing the forms so that we may continue to meet our requirements as an organization to report all our activities. If you have any questions about the forms, please contact Us TOO during regular business hours toll-free at 1-800-808-7866.

Us TOO Chapter Guidelines

The Us TOO Chapter Guidelines are listed and discussed here in four distinct sections, A) Chapter Organization, B) Chapter Communication, C) Policy Compliance and D) Program and Accounting Report.

Section A: Chapter Organization

1. Chapter Core Support. It is beneficial to have more than one person help organize and run the chapter. Us TOO believes that this will help prevent the problem of chapters becoming "inactive" after a leader retires and will ultimately solve the problem of having one person do "all" of the work! Us TOO asks all new chapter leaders to included a list of ten people (including their individual contact information) who have agreed to support and help manage the new chapter.

2. Basic Organization/Governance. To assure that the chapter has a viable, functional organizational structure, Us TOO recommends, at minimum, a chapter creates a Steering Committee that would consist of a chapter leader, an alternate leader and an advocacy contact. Us TOO asks all new chapter leaders to create an organizational structure and share that with us.

3. Community Sponsorship. Each chapter is urged to locate, negotiate and maintain a relationship with a local organizational “sponsor” (such as a health care organization or hospital) to provide meeting facilities and other support.

Section B: Chapter Communication

1. Contact Information. Each chapter provides up-to-date information for the Us TOO network, as found on Us TOO’s website, and for referrals to the chapters. This information is updated for the home office at least annually.

2. Mailing List. Each chapter agrees to develop and maintain a chapter participant mailing list and submit it to the home office once a year to facilitate the most effective and accurate communication possible. Us TOO chapter mailing lists will not be provided to any organization for sales or solicitation purposes.

Section C: Policy Compliance

1. Non-Endorsement. Chapter Leaders and participants agree to follow the Us TOO policy of not endorsing any specific company, product or service.

2. Logo Usage. Chapter Leaders and participants agree to follow the Us TOO policy on chapter Us TOO logo use, which says the Us TOO logo can be used by the chapter with approval of the home office and should reflect the chapter name. Each local chapter name will include Us TOO in the name, and the current Us TOO logo will also be used in all of print materials including newsletters, banners or websites following approval from the home office.

Section D: Program & Accounting Report

1. Program Reporting. Annual Program Accounting/Financial Activities Reporting, will be completed annually.

2. Financial Reporting. Chapter leaders agree to consult with the home office on all financial activity and report all financial activities of the chapter to the home office.

Chapters, for the most part, are created as informal groups and are not incorporated as tax exempt organizations with the federal government or registered as not-for profit organizations in their states. The chapter volunteers may work in collaboration with the home office on raising funds or the chapter volunteers may want to become an incorporated tax-exempt and state registered not-for-profit organization...it is the choice of the chapter leadership. A few chapters have decided to take this course and their experience can be shared with others.

Un-incorporated groups do not have the tax status to open bank accounts necessary to accept tax-deductible donations or raise and handle money.

All financial activity should take place after consulting the home office.

3. Program Best Practices.

a. Medical Advice. Chapter Leaders and participants agree to never give medical advice. Consistent with the Us TOO mission, Chapters provide information and support to help members make informed detection and treatment decisions. Chapters are a link to helpful, reliable information and resources but are not sources of medical advice.

b. Confidentiality. Chapter Leaders and participants agree to respect the confidentiality of those who attend a meeting.