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August 2011
Introduction

Dear Friends,

We are excited that you have decided to commit your time and energy to starting and running a group in your area to address the issues of prostate cancer. All groups that work with Us TOO International commit to:

1) conducting a local community support group,

2) supporting Us TOO’s Mission: 
   *Be the leading prostate cancer organization helping men and their families make informed decisions about prostate cancer detection and treatment through support, education and advocacy,*

3) meeting these Standards and

4) signing the Us TOO “Teaming Agreement”.

Why Standards?

The world has changed and times have changed. Us TOO was incorporated as a not-for-profit organization in 1990 by a group of five men and their family members who were directly affected by prostate cancer. Their motto of “learning to cope through knowledge and hope” still drives our approach of peer support, education and advocacy today.

During the past 20 years, Us TOO has grown and developed and remains governed by a Board of Directors who take seriously the organization’s bylaws which talk about the development and nurturing of local support groups (chapters) as a vehicle for programs to educate and support those diagnosed with prostate cancer, as well as their families/significant others, including those at risk.

Us TOO is committed to quality and meets the National Health Council’s Standards of Excellence which define standards for organizations operating with affiliated organizations and associated groups.

The National Health Council’s Standards of Excellence call for:

1) solid communication,

2) clearly defined relationships and obligations,

3) a commitment throughout the organization to a common mission and goals,

4) use and protection of the corporate name and logo and

5) procedures for dissolution of relationships.

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At Us TOO, these are addressed in our “Teaming Agreement” and in our Policies. In addition, since 9/11 in particular the financial and reporting rules governing non-profit organizations have changed a great deal. The Standards you find here are a reflection of our reaction to such changes.

Clarifying Our Working Relationship

We recognize that the community groups working with Us TOO are developed and led by local volunteers and thus have a strong history of local independence. We do not tightly direct or try to manage each group.

We do, however, ask each group to be aware of and conform to all state and local laws and regulations concerning sales tax reporting and payments, follow these Standards and sign an agreement so we understand our relationship.

These standards, created over the years by Us TOO’s volunteer Board of Directors and staff, are measures to which we can all rise and better serve the growing number of men and their families dealing with prostate cancer. As the organization and local groups evolve the Standards will be reviewed and thus are subject to change.

At Us TOO, we recognize that the local community groups that we work with want to work with us at different levels of involvement. Us TOO’s home office is not here to manage your group, we are here to:

1) facilitate your success by sharing advice and offering training and support from your peers as well as from our office staff and

2) provide resources such as free and low cost materials and items for you to disseminate and use in your community.

In addition to the commitments listed above, and agreed to by all the groups we work with, many groups choose to work with Us TOO International’s corporate or home office on special program initiatives such as Us TOO’s Circles of Love Education & Support Program for Patients and Families (COL) and the Multicultural and Underserved Outreach Program (MUP) or other initiatives to increase awareness and/or develop funds. We welcome and encourage that.

If you are a new group, you will quickly find there are many people at the community level and in the network of groups working with Us TOO willing to help you create, develop and manage your group. While no hard and fast rules exist for the size or format of your group, we do want you to benefit from the collective experience and understanding of what works and what pitfalls to avoid.

Using the basic information provided here and following a proven path, your group can get off to an excellent start and you will find people to help you grow and develop.
Our experience is that each group invariably takes on its own character. Even as part of a larger global network of groups with a similar focus, each group has characteristics unique to its group alone.

Standards for Groups Working with Us TOO International

All groups working with Us TOO should meet these Standards. A group is seen as either a support group or a chapter. **Support groups** focus on providing support group services and some community awareness activities. The groups usually do not handle money or fundraise, are usually unincorporated groups that do not have a Federal tax ID number and are not registered in their states.

Providing services is a core area of interest to Us TOO leadership and this commitment to providing support services is much appreciated and valued. We appreciate that you are in your community helping people make tough decisions, providing the support families need and spreading the word on prostate cancer.

**Chapters** are groups which provide support group services, multiple other services and work on fundraising projects. The groups often work closer and more collaboratively with Us TOO’s home office. They may or may not be incorporated as organizations, have Federal tax ID numbers and may or may not be registered in their states as tax exempt organizations.

This deeper level of involvement is encouraged and valued by Us TOO leadership as our strategic vision for Us TOO includes recognition that the Mission of Us TOO remains only partially accomplished and that we face growing numbers of people at risk from prostate cancer.

There is much more to do and developing more services for more people in more locations will require working closely with groups at the local level to raise more money. Groups may or may not be grandfathered in as incorporate organizations and may or may not be registered as not-for-profit organizations. You will see that today we seek cooperative mutual programming with, and open reporting to, the home office and do not advise separate incorporation or not-for-profit status for new groups.

Sincerely,

Us TOO Board of Directors
Fred Mills, Chairman
Kay Lowmaster, Vice-Chair
The Us TOO Standards

The Us TOO Standards are listed and discussed here in four distinct sections:

A) ORGANIZATION
B) COMMUNICATION
C) POLICY COMPLIANCE
D) PROGRAM AND ACCOUNTING REPORT

SECTION A: ORGANIZATION

1. Core Support.

It is beneficial to have more than one person help organize and run your group. Us TOO believes that this will help prevent the problem of your group 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 leaders to include a list of five people (including their individual contact information) who have agreed to support and help manage the group.

2. Basic Organization/Governance.

To assure that your group has a viable, functional organizational structure, Us TOO recommends, at minimum that your group create a Steering Committee that would consist of a designated leader, an alternate leader and an advocacy contact (to be a point of contact locally on “hot” legislative or advocacy concerns).

Most groups function informally and others in the past have decided to become more formal incorporated not-for-profit, tax exempt organizations. Us TOO has grandfathered incorporated groups and allows their status to stand. However, Us TOO now encourages all new groups to work with the home office before seeking separate corporate status.

3. Community Sponsorship.

Each group is encouraged to locate, negotiate and maintain a relationship with a local organizational “sponsor” (such as a health care organization or hospital to help as a host) to provide no-cost meeting facilities and other support. It is suggested that a simple letter of agreement be developed to outline the relationship between the sponsor and your group.

SECTION B: COMMUNICATION

1. Contact Information.

It is essential that each group provide up-to-date information for the Us TOO website, and to facilitate referrals to your group from the Us TOO 800 Helpline. This information should be updated for the home office at least annually.

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Standards for Groups Working with
Us TOO International Prostate Cancer Education & Support Network

2. Mailing List.

Each group agrees to develop and maintain a mailing list to facilitate the most effective and accurate communication possible. The list should be used in collaboration with the home office. The mailing list should not be provided to any organization for sales or solicitation purposes.

SECTION C: POLICY COMPLIANCE

1. Non-Endorsement.

Leaders and participants agree to follow the Us TOO policy of not endorsing any specific company, product, service or medical provider.

2. Logo and Us TOO International Name Usage.

Leaders and participants agree to follow the Us TOO policy on Us TOO logo use, which says the correct and accurate Us TOO logo and Us TOO International name can be used by the group with prior approval from the home office. When used locally, the logo and Us TOO name should reflect your local group’s name. The group’s name should be approved by the home office and reflected on your group’s Us TOO Charter.

In the past, local groups could use the Us TOO name and logo on print materials including letterhead, newsletters, banners or websites. Moving forward the new Us TOO support group or chapter logo developed for local group use should be used to identify your group. This will assure proper organizational branding and identification.

SECTION D: PROGRAM AND ACCOUNTING REPORT

1. Program Reporting.

Program activities reporting should be done annually. All groups working with Us TOO agree to do, at minimum an on-going support group. Many groups are active on the program front with additional activities such as programming for family members such as women, special populations such as African Americans or awareness and outreach projects. It has become the mark of outstanding organizations to make the public aware of what a group does, and the results as well as impact of donors’ support for the organization. Program reporting will assure a more complete picture of what Us TOO and the groups working with the home office do and accomplish.


All group leaders agree to consult with the home office on all financial activity and report all financial activities of your group to the home office. Us TOO has a history of providing free and low cost materials for local groups and has not...continued
required fundraising nor levied dues or charged fees to be involved as a group working with Us TOO. That remains true today.

Us TOO expects all groups to be aware of and conform to all Federal, state and local laws and regulations concerning income and sales tax reporting and payments. For the most part, local groups working with Us TOO are created as informal groups and are not incorporated or recognized as tax exempt organizations by the federal government or registered as not-for-profit organizations in their states.

Your volunteers may choose to work in collaboration with the home office on raising funds for Us TOO and/or for your local group’s activities. It is expected that local groups engaging in raising funds using the Us TOO name be able to use 75% for local mission-related program activities and share 25% of net (after expenses) funds raised for home office activities.

Unincorporated groups do not have the tax status to accept tax-deductable donations, to open bank accounts or to raise and handle money as they are not legal entities. Groups have the benefits of working with the home office to utilize Us TOO’s tax exempt status, accept gifts as tax-exempt donations and avoid the pitfalls of personal liability, taxes and/or potential fines.

As previously mentioned, in the past some local groups became incorporated tax-exempt and state registered not-for-profit organizations. Those groups who are incorporated need to take on the responsibility of completing their own tax forms and/or sharing their local bank account information with the home office. New groups however are encouraged to work with the Us TOO home office and conduct activities cooperatively and use the Us TOO corporate tax status.

3. Program Best Practices.

a. Medical Advice.

Leaders and participants agree to never give medical advice. Consistent with the Us TOO mission, local groups working with Us TOO provide information and support to help members make informed detection and treatment decisions. Local group volunteers are a link to helpful, reliable information and resources but are not sources of medical advice.

b. Confidentiality.

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