

10 Steps to Form a Patient Support Group:

1. **Identify people** – Find people who are interested in getting involved - like dystonia patients, family members, friends. It is more fun if you are working in a team. Form an organising committee and meet to discuss what you want to do and how to do it.
2. **Identify what you want do.** Decide on the aims of your organisation, like giving information and support to patients and their families, spreading knowledge of dystonia, promoting research.
3. **Identify medical specialists.** It is helpful to have support from a doctor specialised in dystonia. He or she can help to promote the organisation, help with a meeting room at hospital, or come and speak at a meeting.
4. **Formal structure.** It is a good idea to have a formal but simple structure with your aims and rules of management, and these are detailed in the document called the statutes. This will allow the organisation to function transparently and professionally. If you intend to register your organisation with a national authority, find out in advance what information or structure the registering authority needs to see in the constitution. You have to look into what rules apply in your country and whether legal advice is needed to write a constitution.
5. **Membership fee** – How is the work of the organisation going to be funded? Through grants, donations, membership fee? Any membership fee should be at a fairly low level since you want to have as many members as possible.
6. **Identify possible sponsors.** Look into how you can collaborate with the botulinum toxin and medical device companies and other organisations, and ask them how they can support your organisation. There are many ways of collaborating on projects which also help the sponsor, without losing your organisation's independence or credibility.
7. **Think of how you can share your work in your country.** Do you know somebody working within the media? Maybe one of your 'team' could write an article about dystonia and the new patient organisation, and find ways to get it published?
8. **Communication** – web-site, newsletter, leaflet, social media. It is a good idea to have information leaflets to give out to clinics, patients and their families. Especially if you have a membership fee, a newsletter helps members to feel that they are getting something useful from the organisation.
9. Bring your team together to **create an initial strategy** from items 1-8.
10. **Call the first meeting** when your team is ready.