

## **Help & Check List**

## **On-line activities**

- 1. Jump for Dystonia Facebook page: <a href="https://www.facebook.com/jumpfordystonia">https://www.facebook.com/jumpfordystonia</a> this is where all the activities/jump photos are collected and shared.
- 2. Photo Uploads can be done in 2 ways on the JUMP for dystoni facebook page:
  - as a message on the wall
  - on the contest page <a href="https://www.facebook.com/jumpfordystonia/app\_340493986057345">https://www.facebook.com/jumpfordystonia/app\_340493986057345</a> by submitting a photo together with e-mail address. Share the photo with friends and try and get as many likes as possible and you can win a skydive. There are 4 skydives to win. These are chosen in January, April, July and October. The skydive will take place where you live.
- 3. Encourage people to use hashtags: #jumpfordystonia #dystoniaawareness #teamjumpfordystonia for all jumpfordystonia posts on facebook, twitter, instagram and other social media.
- 4. Encourage others to jump by nominating people to jump by posting:
  - "I nominate ... "name"... to jump for dystonia"
- 5. Suggestions for key words/messages to use:
  - the little known brain disorder
  - causing involuntary muscle contractions
  - affecting millions of people worldwide
  - "I have jumped for ...name/my mother... who has dystonia and to raise more awareness.
  - Dystonia leads to disability, stigma and decreased quality of life for patients and their families.
  - Dystonia a little known brain disorder causing painful spasms.
  - We know more than half a million Europeans live with dystonia, but it could be as many as 3 millions...
  - Can affect one part of the body or several muscle groups
  - Can affect men, women and children of all ages and backgrounds
  - •...name...is taking up the challenge to jump for dystonia

## In Real Life Activities

- 6. Suggestions for JUMP events/activities:
  - at local/regional/national dystonia support meetings
  - at General Assembly/board meeting of National Dystonia Associatons and any other organisation
  - ask your sponsors if they are interested in holding an event.
  - contact media (radio, TV, newspaper) local/national level and tell them about this unsual awareness campaign.
  - bring the roll-up to the main square in your city, maybe on a Saturday in springtime, when there is a lot of people in town and ask people to jump, take photos and talk about dystonia
  - organise a flashmob

- approach the Parliament in your country and investigate the possibility of organising a jump for dystonia event. Were there any MEPs from you country who jumped last November in Strasbourg? They might be interested in supporting you at the national level for an event. Check with Monika Benson if you need to connect with any of the MEPs who already jumped in the EU Parliament in Strasbourg.
- at dancing/singing events, maybe in combination with fund-raising for your local group/project.
- at health activities/events/exhibitions
- at your work-place
- ask to be invited to schools to inform about dystonia and jump, as the following example from the US: for your local group/project
- at family and friends gatherings, wish for a JUMP for dystonia as a birthday gift...
- 7. Do you know anybody famous in your country that you could ask to jump for dystonia and support your cause? Much easier to spread the word with famous faces.
- 8. We appreciate any ideas you might have to add to this list. Please send it to: sec@dystonia-europe.org