



## CHORDOMA CHAMPION PAGES SETUP AND USER GUIDE

Though the chordoma community is relatively small, by joining together we have the power to make a major impact. Champion Pages provide an easy way for every member of the Chordoma Community to share their story, connect with others, and help the Chordoma Foundation accelerate the search for a cure. This guide will help you create an excellent Champion Page, and effectively use it to reach your fundraising goals. The Chordoma Foundation depends on the grass-roots fundraising of Champions and their families, so we thank you for your support.

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## PURPOSE OF CHAMPION PAGES

**Find and connect with others** – The champions site allows you to locate other members of the chordoma community on a map and communicate with them directly through their profile page – even if you don't have their contact information. This feature is meant to foster new supportive relationships, and local gatherings of nearby chordoma community members.

**Express yourself** - Your Champion Page is your own spot on the Chordoma Foundation Website to share your story, experiences and hopes with friends, family and others. Chordoma affects everyone in different ways (physically, emotionally, socially); Champion Pages tell how chordoma has impacted the lives of each individual.

**Raises awareness** – As a rare disease, chordoma is unknown or neglected by most people. In order to make progress towards a cure, awareness about chordoma, and the dozens of other rare and neglected cancers must be heightened. Champion Pages show the world the human impact of chordoma, and the motivation of members of the chordoma community to help find a cure for this condition that so directly impacts their lives.

**Enables your supporters** – In today's interconnected world we all interact with a large network of people. Champion Pages allow people who care about you to help you reach your fundraising goals by easily donating on your behalf. Sharing your Champion Page with your network of supporters will allow them to express their good will and concern in a way that will accelerate the search for a cure.

**Makes Fundraising Easy** – Champion Pages allow you to set a fundraising target and track how much money you've raised. Every time someone donates through your champion page you will move one step closer to reaching your target. Your Champion Page has a unique URL that you design (e.g. <http://champions.chordomafoundation.org/john>), which can be shared easily with people you know via mail, email, social networks, or even by word of mouth. Importantly, Champion Pages allow you to see who has contributed as a result of your efforts, and makes it easy to thank these people directly.

## CREATING YOUR PAGE

### SETUP INSTRUCTIONS

1. First login or create an account at <http://champions.chordomafoundation.org/session/new>
2. When you login for the first time you will see a dashboard with a bullet list of status items. Status items in bold require your attention.

3. Click **setup your contact information**.
  - a. Enter your address – this will allow you to appear on the chordoma community map. **NOTE:** the map displays a pin in your city, but never displays your actual address.
  - b. Indicate your relationship to the cause
  - c. Set a fundraising target
  - d. Select your personalized URL – this is an easy to remember shortcut to your page that you can share with people you know.
  - e. Indicate whether your profile can be listed among member search results – your profile will always be visible at your personal URL
  - f. Indicate whether you want to display the amount of money that you’ve raised
4. Next, click **setup your profile page**. This will take you to the “Information” tab of your profile page. Here you will write a few paragraphs about **your story** and **your reason for fundraising**. See below for guidance on what to write.
5. From here you can also click **Change Your Picture** to upload a profile picture. This is not required, but we recommend it. (Please make sure pictures are appropriate for all audiences)

## DECIDING WHAT TO WRITE

We recommend starting your champion page by answering the questions below in a word processor (even if you don’t include all the information it can be a useful personal exercise.) **DO NOT try to write the story while creating the web page. The site may “time out” and you could lose all of your work.** As you write remember to save.

### 1) You story

- a. Who are you? What do you do? What defines you aside from chordoma?
- b. What is your relationship to chordoma? (did it affect you directly, or did it affect some one you care about?).
- c. How long have you been dealing with chordoma?
- d. Describe the experience.
- e. How has chordoma affected you physically, emotionally, socially, spiritually?
- f. What have you learned from dealing with chordoma?

## 2) Your reason for fundraising

- a. What do you hope for?
- b. What would a cure mean to you?
- c. Why do you support the Chordoma Foundation?
- d. Ask people reading your page to help you reach your fundraising target by making a donation.

## WRITING & STYLE GUIDELINES

Please keep in mind that your page is available to the public and will be viewed by many people:

- Your friends, family members, and coworkers
- Other chordoma patients
- People of all age ethnicities, and nationalities
- Members of the media
- Donors and potential donors to the Chordoma Foundation
- Healthcare professionals like nurses and physicians (possibly your own physician)
- Scientists and Researchers

Therefore, please design your page to be appropriate for all of these audiences. For example, you should not write anything that you would not feel comfortable telling directly to your doctor, a coworker, or anyone else. Also keep in mind that anything that you write reflects on the Chordoma Foundation and the entire chordoma community.

### Content

- In general please be considerate of others when creating your page. Please do not write anything, or upload a picture, that others would find offensive.
- **Do not give medical advice.** Do not share doses or dosing schedules for drugs that you have taken or are taking as this can be taken as advice
- **Do not suggest or discourage the use of any therapy, physician, or hospital**
- **Do not share grievances with your doctors, hospitals, insurance company, employer or anyone else.** We understand that dealing with the medical system can be very frustrating, however champion pages are not the appropriate venue to point out mistakes, faults, or disputes you have experienced in the course of your experience with chordoma.
- **No cursing or profanity**
- **Nothing insulting, derogatory, or inflammatory**

## Style

- Writing should be clear, understandable, and grammatically correct
- Do not use abbreviations as some readers will not understand what they mean
- Please do not write IN ALL CAPS as this is the equivalent of SHOUTING and makes your page hard to read
- Keep in mind that web pages are much easier to read if they contain several short paragraphs instead of one long paragraph.

## USING YOUR CHAMPION PAGE

### COMMUNICATING

Champion pages give you a number of ways to communicate with online members, and with other people you know.

1. **Journal:** use this feature to keep friends and family updated about your health and treatment, or that of a loved one. Friends and family can subscribe to receive an email whenever you update your journal. We encourage you to use this instead of CaringBridge or CarePages during a hospitalization.
2. **Email:** to contact any other member of the community click on the Email link below their profile picture. This will take you to a form which will allow you to create an email for this person. The email will be sent through our system, and if they wish to respond they can email you directly.
3. **Guest book:** this feature allows anyone to leave a public comment on a Champion's Page. It is a great way for community members to communicate with each other or for friends or family to show their support. One does not need to create an account to be able to leave a comment, however you have complete control over your page and can delete any comment if you wish.

### FUNDRAISING

The most powerful source of funding for a rare disease like chordoma comes from the people who love, care about, and support chordoma patients/survivors. Champion pages are designed to empower you to effectively raise money from people you know both online and offline.

One of the easiest and most effective ways to raise money is through a letter writing campaign. We encourage you to send an annual letter and/or email requesting support for the Chordoma

Foundation from your friends and family. For many, these letters have been very successful, usually generating \$2,500 - \$10,000 or more. It is important to set a realistic target – the default is \$5,000 but you can change this to reflect what’s right for you.

One of the biggest keys to successful fundraising is follow-up: to thank donors and remind those who have not yet donated. When someone you know makes a donation a heartfelt thanks from you will be much more meaningful than a letter from the foundation. Similarly, if people you solicit do not donate you should gently remind them how important it is to you. Many people get busy and simply forget to mail in their check – a polite reminder after a few weeks is usually appreciated.

**However, to follow up you must know whether the people you’ve solicited actually donated or not.** We’ve solved this problem by tying your dashboard directly to our donor database, and building “smart” software to display donations that are credited to you.

There are three ways a donation can get credited to you:

1. **Champion Page Donations:** when someone donates through your Champion page you will automatically be credited with their donation.
2. **Tributes:** any time someone makes a donation specifically designated in your name, whether by credit card online or by check offline, you will also receive credit for it.
3. **Matched Donations:** often times people you solicit will simply make a donation without indicating that the donation is in your honor. To match these donations to you, our system compares addresses that you provide against our donor database. If there is a match then the appropriate donation will be credited to you. (**NOTE:** addresses that you provide are never used for solicitation purposes and are stored securely, separate from our donor database).

Donation’s credited to you will be displayed on your dashboard page. When you first sign up our system will search for donations that had previously been made in your honor and will display these in your dashboard. Please be aware that donation matches are not made in real time, and may take a day or more to appear in your dashboard. Only the donor’s first and last name and the date of the donation will be displayed – for privacy, the donation amount and donor’s contact information will never be revealed.

Each time that a donation is made on your behalf, you will receive an email notification with a link back to your dashboard. From there, our system will guide you through the process of thanking each donor.

**COMING SOON:** If you do not have the donor’s contact information you will be able to send a thank you email through your dashboard.

If you have any questions please email [feedback@chordomafoundation.org](mailto:feedback@chordomafoundation.org)

## FREQUENTLY ASKED QUESTIONS

Q: How do I view a list of all champion pages?

A: From the Pages tab, click on the “browse all” link next to the search button.

Q: Why do some profiles not appear on the map?

A: If a champion has not entered their address, then they will not appear on the map

Q: Is it safe for champions to enter their address?

A: Yes, the map pin is displayed at the city center, not at the champion’s actual street address.

Q: Why doesn’t my fundraising total increase an online donation was made through my champion page?

A: Due to the complexity of matching donations, fundraising totals are only updated once per day. We’re working to decrease the delay.

Q: What if I don’t want people know how much money I’ve raised?

A: From the Edit Your Details tab on your champion page, you can turn off your fundraising visibility.

## POLICIES

1. Use of Champions Pages is governed by the site’s [Terms of Use](#)
2. The Chordoma Foundation’s privacy policy applies to all personal information entered in champion pages [Privacy Policy](#)
3. The Chordoma Foundation’s website is not intended for children under the age of 13. As such, Children under the age of 13 may not create Champion Pages. The parents of children are permitted to create Champion Pages.
4. Pages are routinely monitored for inappropriate content. If inappropriate content is found on your page you will be notified and asked to remove it. The Chordoma Foundation reserves the right to edit or remove all content on champion pages without notice.