

# The Million Dollar Bike Ride

May 7, 2016

The Penn Medicine Center for Orphan Disease Research and Therapy  
Team “Raring to Go for CHI”

Thank you for joining “Raring to Go for CHI” and the Million Dollar Bike Ride! Your participation is so important. Every dollar you raise will help to fund congenital hyperinsulinism research.

The first step is to register for the ride. Please email me (Leo) at [Leo.E.Brown@gmail.com](mailto:Leo.E.Brown@gmail.com) once you have completed this step or if you have any questions.

## Registering for the ride and joining the CHI team.

- Go to [www.milliondollarbikeride.org](http://www.milliondollarbikeride.org) and click on [Cyclist registration](#).
- Select “Cycling With Fundraising” or “Cycling Without Fundraising.” “With Fundraising” means it only costs \$25 to register but you must raise an additional \$100 and create a “Raring to Go for CHI” fundraising page using Penn Giving Pages. This is fun, pretty easy, and a great way to raise more funds for HI research. Alternatively, you can sign up as “Cycling Without Fundraising.” In this case you pay \$50 to register but don’t have to create a page and do more fundraising. If you want to donate more than \$50 but do not want to fundraise beyond yourself, just make an additional donation to on the CHI website: <http://congenitalhi.org/donate/>
- Choose your “Route Preference” – 11, 34, or 75 miles. Members of the team will be riding all three distances, so choose whatever is best for you!
- For your “Team,” **select Raring to Go for CHI** (that’s us!).
- Add your personal information. **It is very important to use the same email address for everything related to the ride** – that includes both this registration and the fundraising page that you build. Your email address is how Penn will make sure the money you raise counts toward our congenital hyperinsulinism research fundraising goal!
- Look in your inbox for the email confirming your registration.
- Email Leo ([Leo.E.Brown@gmail.com](mailto:Leo.E.Brown@gmail.com)) to let him know you’ve registered.

## Setting up your CHI Fundraising Page

To set up your fundraising page, simply follow the instructions on this website: <http://www.milliondollarbikeride.org/fundraising-setup/>. The screenshots and arrows should guide you through the process, but here are a few things to keep in mind as you follow the online instructions. Please email Leo at [Leo.E.Brown@gmail.com](mailto:Leo.E.Brown@gmail.com) once you have completed this step to let me know you have registered and if you have any questions. By emailing Leo, we will be able to make sure the funds you raise fund the “Raring to Go for CHI” team.

- When you are prompted to “Create a Page” and “Click ‘Go,’” click on the fourth (bottom) “Go” button, rather than the one indicated by a red box in the
- Once you’ve clicked “Go,” type whatever you wish in the first five fields under “Fundraising Information.” All of this can be personal and specific to you -- it is what your friends and family will see when you ask them to donate. You can also take a look at Julie Raskin’s personal page (<http://givingpages.upenn.edu/julieraskinforchi>) to get other ideas. You are free to use any text you want from her page as well. What follows is what I wrote on my page. Come up with something specific to you. You might want to use my first sentence and add something:
  - Possible text for the “Description” (modify to match what you would like to share about your own circumstances): *Help me raise money to fund innovative pre-clinical or clinical studies designed to improve the diagnosis, therapy, or quality of life for those affected by congenital hyperinsulinism (HI). This is the disease I was diagnosed with as an infant and why I have diabetes today. With more research funding, HI can be better understood and better managed!*
- Save your custom URL – this is how you can share your fundraising page with family and friends!
- Be sure not to click the “Fundraising event” box.
- Directly under “Select a Fund,” there is a “More Funds” button. Click this button, type in “Million Dollar,” and click “Search.” When you see the Million Dollar Bike Ride, click “Select.”

After you’ve clicked “Continue,” enter your personal information and click “I Agree,” and “Register.” Then, you will receive instructions by email to create your fundraising page.

When you are ready to fill in the text for your newly created fundraising page, you can include whatever you think will appeal most to your friends and family. Just click “Edit” on any of the sections. There’s no need to fill every single box with text, so if you aren’t going to use one, just click “Hide Box” and it will disappear. Don’t hesitate to experiment with this; you can always unhide it later!

Choose a title that will make sense to potential donors. My page is called “Leo Cycles for CHI.” Feel free to upload the the CHI logo, as your page’s picture.

Here are some ideas to get you started on the text. For the first section, I wrote the following:

### ***Raring to Go for CHI***

*Raring to Go for CHI will ride alongside other teams in The Million Dollar Bike Ride to raise money for congenital hyperinsulinism (HI) research. CHI (Congenital Hyperinsulinism International) is a fantastic organization that brings together the HI community and partners with researchers to advance efforts to diagnose and treat the disease. The Million Dollar Bike Ride will raise research funds for the Center for Orphan Disease Research and Therapy at Penn which will match the money raised by each team.*

*Congenital Hyperinsulinism (HI) is a life-threatening genetic disorder that causes severe low*

blood sugar (*hypoglycemia*) in infants and children. Any donations in honor of our team's efforts will help us fund HI research.

Learn more about HI at the CHI website! <http://congenitalhi.org/>

You might also want to include a bit of your personal story, but it's certainly not necessary. For example, here is what I wrote for my second section, since most of my friends know about diabetes, but not HI.

***Wait ... I thought you have diabetes!***

*I do! That's just it. But first, I was born with HI. To treat that condition, a team of doctors at Mass General Hospital removed most of my pancreas in two surgical operations. Diabetes is an eventual consequence of that treatment. In fact, I am very lucky to make off with few medical complications aside from diabetes, since infants with HI are at risk of severe neurological and developmental challenges as a result of prolonged hypoglycemia (low blood sugars).*

If you'd like to include only the first section, a modified version of that, or something altogether different, that's perfectly fine. The important part is to share with potential donors that we are riding our bikes **to raise money for congenital hyperinsulinism research.**

Finally, in my third paragraph, I included a bit of information about The Million Dollar Bike Ride. After all, that's the main event, and I want everyone to know that I'll be cycling around Philadelphia in support of this important cause. So here is what I wrote:

***The Million Dollar Bike Ride***

*The Million Dollar Bike Ride, organized by The Penn Center for Orphan Disease Research and Therapy and Rare Disease Cycling, is the 1st annual cycling event to raise money for world-wide rare disease research. The ride begins and ends at Highline Park, 31st and Chestnut Streets in Philadelphia. At 9 a.m. on Saturday, May 3, members of Raring to Go for CHI will set off for 11, 35, and 73 miles. We'll all be preparing for this event over the next months by raising money and, for everyone who is able, partnering with the Therapy and Rare Disease Cycling team to train!*

As you will see, there are various other ways to customize your fundraising page. Have a look around and make it your own!

If you have questions about setting up your page, don't hesitate to email me (Leo) at [Leo.E.Brown@gmail.com](mailto:Leo.E.Brown@gmail.com). Once you've built your fundraising page, email me and you're all set!

Thank you again for participating in The Million Dollar Bike Ride and joining team Raring to Go for CHI!