

## 2018 Million Dollar Bike Ride Event Policies

Event date: Sunday, May 20, 2018

1. **NEW Eligibility Guidelines** for Rare Disease-Focused Teams' future participation (2019 event and beyond) for the Million Dollar Bike Ride will be determined by 3 factors. *Please note, these guidelines are subject to change:*

- 1) **Performance:** The 20 top performing teams in the 2018 MDBR will be automatically grandfathered into the 2019 MDBR. Performance is based on a) number of dollars raised and b) number of participating cyclists. Teams will be ranked by these two factors, and the top 20 will automatically receive a spot in the 2019 event.
- 2) **New Teams:** Up to 3 additional new teams will be included in the 2019 MDBR.
- 3) **Pool:** Additional teams will be entered into a pool, and 5 will be chosen at our discretion. This pool could include both new teams *and* existing teams that did not make the cut.

**Teams include:**

- 1) Any group (formally organized as a foundation, or not) committed to advancing research for a rare disease, or group of related rare diseases.
- 2) Willing to recruit at least 10 individuals to participate in the event as cyclists and/or volunteers.
- 3) Capable of raising at least \$20,000 on behalf of their team (including registration dollars and donations).
- 4) Subject to approval by Center Director, Jim Wilson.

2. **Registration**

1) **Cyclists**

i. **Registration:** there are two ways to participate in this event. All will be required to sign a liability waiver. Anyone 16 YO or older can participate as a cyclist.

1. **Registration only:** One can realize full benefits of riding in the event by paying a registration fee without a commitment to raise additional money:
  - a. \$60 before March 31, 2018
  - b. \$80 from April 1, 2018 – May 13, 2018
  - c. \$100 day of event
2. **Registration with fundraising:** registration is \$25 and requires a minimum fundraising commitment of **\$250**. It is expected that the minimum is met by May 20<sup>th</sup>, 2018.

**Affiliation with Disease-Focused Teams:** At the time of registration, each person will be asked to affiliate with a Disease-Focused Team based on a drop-down menu of registered Teams. If a person does not wish to affiliate with a specific team, they can be "independent". The money raised by the independent group will be split amongst disease teams.

***\*100% of registration and fundraising money will go to the Disease Team's research fund.***

ii. **Jerseys and T-Shirts:**

1. **Event Jersey:** Each cyclist who registers and commits to fundraising will receive a complimentary professional-style cycling jersey designed to commemorate the 5<sup>TH</sup> Annual event. IF you register before March 12<sup>th</sup> (date approximate) you are guaranteed to receive the sized-jersey you select during registration. For those who register after this date, a jersey in your size will be available after the event.
2. **Event T-Shirt:** Each registered cyclist will receive a complimentary event t-shirt. Preferred size is guaranteed for all who register prior to April 20<sup>th</sup> (date approximate).

2) **Volunteers**

- i. **Registration:** A separate registration site will be made available to volunteers. There is no cost for volunteers to participate, although each must sign a liability waiver. Volunteers must be 18 YO or older.
- ii. **Roles:** The following general categories of volunteers will be needed:
  1. start/finish area
  2. course marshals
  3. aide station personnel
  4. ride leader/sag support
- iii. **Perks:**
  1. All volunteers who register before April 20<sup>th</sup> will be provided a t-shirt of the desired size at the time of registration. A limited number of t-shirts will be available for those who sign up after April 20, 2018 and will be provided at the time of check in on a first-come, first-served basis.
  2. All volunteers will be provided with a coupon to get access to the post-event meal.

3) **Disease-Focused Teams**

- i. **Registration:** a web link will be provided for each team to register
- ii. **Roles:**
  1. **Team Captain:** the individual who is responsible for working with event staff to recruit cyclists and volunteers to support their team. This person will preferably ride in the event, although not necessary. Team captains collaborate with representative from sponsoring Foundation to define scientific content of grant RFAs.
  2. **Representative of sponsoring Foundation:** this person should have the authority to represent the sponsoring Foundation in all matters of the collaboration. This person can also serve as Team Captain. An important aspect of this position is to work with the Team Captain to define the research focus of your team's RFA.
- iii. **RFA Content:** On the registration site, you will be provided with two options (please note, this can be changed at time of RFA release):
  1. Category A = anything directed toward the development of a treatment or cure
  2. Category B = specific subcategories of research (you can select multiple sub-categories)

- a. [if B, then...]
  - i. Diagnostics
  - ii. Biomarkers
  - iii. Model systems
  - iv. Cell therapy
  - v. Gene therapy
  - vi. Protein replacement therapy
  - vii. Small molecule therapy
  - viii. Natural history
  - ix. Genetics
  - x. Other \_\_\_\_\_ [must fill in if selected]

### 3. Management of Grant Awards

- 1) **Sources of Grant Revenue:** There are three sources of money raised for a Disease-Focused Team.
  - i. **Registration fees:** 100% of registration fees from each cyclist goes towards their team's fund.
  - ii. **Direct contributions:** donors can contribute directly to a Disease-Focused Team by check, credit card, or matching company gifts. All credit card donations are processed via Penn GivingPages, a fundraising platform that all teams will utilize.
  - iii. **Matching Funds:** Each Disease-Focused Team that raises a minimum of \$20,000 will be eligible for dollar-for-dollar matching funds from the Orphan Disease Center (ODC), up to a maximum of \$50,000.
- 2) **Grant Program:** The ODC will be responsible for managing the grant program as follows:
  - i. **Solicitation:** On or before August 1, 2018, a Request for Applications (RFA) will be broadly distributed to the international scientific community describing the programs and funds available as a result of the event. The RFA for each disease grant will solicit applications focused on the area defined by the Disease Team/Foundation. The ODC will work with the sponsoring Foundations to assure the solicitation is distributed to the appropriate stakeholders. Note – this is an international solicitation and is not limited to scientists from an institution or country.
  - ii. **Review:** ODC will assemble a team of scientists to review the grant applications drawing from Penn scientists, advisors from other institutions, and recommendations from the Disease Team/Foundation. The grants will be reviewed based on merit and relevance to the RFA.
  - iii. **Award:** Final decisions will be made by December 1, 2018 (date approximate) with funding to commence January 1, 2019.
  - iv. **Post award management:** ODC staff will distribute funds to awardees and monitor spending and progress of the research. The sponsoring Foundation will receive a copy of final scientific report of grant awarded on their behalf.
- 3) **Awards:** The total amount of money raised on behalf of a Team will dictate the number of grants that will be awarded for each disease. All awards will be for pilot grants (5 page max) that range from \$40,000 to \$100,000 for one year; up to 10% indirect costs are allowed.
- 4) **PLEASE NOTE, NEW POLICY:** If a Disease Team raises less than \$20,000, they are not eligible for the match, and thus the total funds raised will be directed back to the Orphan Disease Center.