# SHADOW JUMPERS IND YOUR SHADOW 2019





experience. The trip planning was excellent from start to finish, with minimal effort needed on our part. It was def a once in a lifetime opportunity and we got to experience so many activities that we never thought would be feasible for our family. Initially the kids would feel a little self-conscious like normal but as the fun began, they got so sidetracked by the excitement and thrills of being at Disney, they quickly forgot about their cover-ups and enjoyed being kids! All the staff at Disney World are excellent and made us feel welcomed and supported. Our VIP tour guide went above and beyond getting us specialized treatment, and assuring we saw and did any activity that the kids wanted. Even more important, he was very conscientious of the kids' EPP. He kept them in the shade and had UV protective umbrellas to keep them blocked when walking about. He was so considerate, fun and knowledge. He absolutely made the experience something we will never forget."

#### WHO IS ELIGIBLE

All children and their families in the USA suffering from Erythropoietic Protoporphyria between the child ages of 5-17. Shadow Jumpers is dedicated to making EPP families adventures come true.

This year's Find Your Shadow
Program will be selecting one
family for an all-expenses paid trip
to Walt Disney World in Orlando,
Florida. This trip will include
transportation, lodging, meals and
making every step possible in the
park EPP friendly. We'll handle the
sun, you can bask in all the wonder
of Mickey, Minnie and the gang!

Shadow Jumpers is hopeful that, by finding creative ways to help kids and their families take on their wildest sunlight adventures, we can create a significant positive impact on a child and their family.

#### FIND YOUR SHADOW REQUEST PROCESS

Submissions will be selected once a year. The deadline for submissions is Friday March 15<sup>th</sup>, 2019 and a family will be selected on Saturday April 6<sup>th</sup>, 2019.

#### 1. FAMILY SUBMISSION

This application must be submitted in its entirety and sent to Shadow Jumpers by the deadline given on the APF website. Submission can be via email or by mail in.

#### 2. SELECTION

All family applications are reviewed in collaboration between Shadow Jumpers and the American Porphyria Foundation.

A group of families will be skyped interviewed in part of a final round selection process.

Families not selected as our recipients can re-apply every year.

#### 3. THE MOMENT

Once a family has been selected, the child's family will be notified by email. Any additional calls or interviews will be conducted to help make their trip as specific to the families hopes as possible.

#### 4. FIND YOUR SHADOW

Once all details have been confirmed, Shadow Jumpers team sets out to create an unforgettable experience.



riease print and complete all sides of this request form, sign and scan/email to <a href="mailto:craig@shadowjumpers.org">craig@shadowjumpers.org</a> or mail to

American Porphyria Foundation
Attention: Shadow Jumpers
4915 St. Elmo Avenue, Suite 105. Bethesda, Maryland 20814
CHILD'S DETAILS

Name
First Last Child's Gender M F
Child's DOB Child's Age
Child's Address
City State
Zip code
PARENT / GUARDIAN'S DETAILS
The child resides with
Mother Father Joint Legal Guardian
MOTHER / LEGAL GUARDIAN'S DETAILS
Name
First Last
DOB
Address (if different from child's)
City State
Zip codePhone
Email
FATHER / LEGAL GUARDIAN'S DETAILS
Name First Last
DOB
Address (if different from child's)
City State
Zip codePhone
Email
SIBLING DETAILS
Full Name M/F Age DOB

### **CONTACT FORM**

#### **LOOKING AFTER YOUR PRIVACY**

Your right to Privacy is important to us. This statement explains your privacy rights and our obligation and rights in relation to collection and use of your personal information.

#### You and your child's right:

- You are not required to give us any personal information in your request form or any other document or communication relating to this submission. However, without this information, we may not be able to process your application.
- You may request access at any time to personal information held by us about you or your child and ask us to correct, amend or update it if you believe it is incorrect or out-of-date.

#### How The Shadow Jumpers may use your family information:

- To Process your application
- To administer and manage your submission
- For internal use to determine your child's submission and establish your family needs regarding the submission.

#### Disclosure of personal information:

We may disclose your child's personal information if it is necessary in the following instances;

- If you request or authorize us to do so or where the law requires us or permits us to do so.
- To our external service providers and contractors that provide good or services for the Shadow Jumpers project to grant your child's request.
- Insurance company, or travel agent.





#### "FIND YOUR SHADOW" 2019 SUBMISSION

#### Walt Disney World Resort, Summer 2019

On a separate sheet of paper, please provide us with some information on the following;

- The Child with EPP
- The family of the Child
- Why this family should be selected for "Find Your Shadow"
   2019

We encourage you provide any and all photos, materials you would like to add to this submission. The more creative the better!

Please include all the following information when sending your application to <a href="mailto:craiq@shadowjumpers.org">craiq@shadowjumpers.org</a> or

American Porphyria Foundation
Attention: Shadow Jumpers
4915 St. Elmo Avenue, Suite 105, Bethesda, Maryland 20814

- Child and Family background / story
- Signed Consent Form
- Contact Form

## SIGNED CONSENT

This section must be signed for Shadow Jumpers request to be processed. I/we acknowledge that no promises or assurances whatsoever have been made to me/us by any representative of Shadow Jumpers regarding the request submitted. I/we understand that the granting of any request and the authority to participate therein by any person Is contingent upon the approval by the APF and Shadow Jumpers and compliance with all conditions, qualification, pre-requisites and restrictions imposed by the APF and Shadow Jumpers.

I/ we also acknowledge that, should the request be granted, no negotiation pertaining to the request with any third parties by myself/ourselves or by representatives on my/our behalf will be undertaken without prior consent and express agreement of the APF and Shadow Jumpers in

writing. Should such consent and agreement be provided, then I/we further acknowledge that I/we will keep the APF and Shadow Jumpers informed in writing of the progress and results of such negotiations as soon as practical.

I/we hereby authorize and request the herein mentioned medical specialist to release to the APF and Shadow Jumpers, all information required in relation to the health of the child or other interested party e.g. Travel Insurance Provider. A photocopy of this authorization shall be valid as the original. I/we declare that I/we have read and understood the Privacy Statement outlined in this form and I/we consent to the collection, use and disclosure of personal information in accordance with the Privacy Statement. Where I/we have provided information about another individual, I declare that the individual has been made aware of that fact and the contents of the Privacy Statement.

Signature of:

Mother Father Legal Guardian	
X	
Print	
Date://	



