



THE
Stuhlsatz
FAMILY
WICHITA, KANSAS
★ 2018 ★
Recipients

"Our Find Your Shadow trip was out of this world. Initially the kids felt a little self-conscious like normal but as the fun began, they got so sidetracked by the excitement and thrills of being on our sun proof vacation at Disney. Our VIP tour guide 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. Shadow Jumpers put us in a suite in Animal Kingdom so we could watch the animals from our balcony (and more importantly, in the shade and out of the afternoon sun."

THE
McKillop
FAMILY
BLUE POINT, NY
★ 2019 ★
Recipients



"Thank you so much to Shadow Jumpers for helping us re-do our Disney trip a few years ago when our daughter Morgan got a terrible reaction. Their knowledge of where to stay, what to wear and how to balance out our days really made this the safest (and most fun) vacation we have had. The tour guide they set us up with was knowledgeable about our EPP and took us through so many different ways around the park to combat the sun. The resort they picked for us was with EPP in mind, having a late-night water park that our kids happily took advantage of. As we shadow jumped over the course of our long weekend, we even got help in the form of perfect rainy weather here and there. We're so excited to see who Shadow Jumpers helps next!"



WHO IS ELIGIBLE

All children and their families in the USA suffering from Erythropoietic Protoporphria 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 kids who are attempting to do something they have always wanted to try but may have been holding off attempting because of their EPP. Whether that is attempting recess, an outdoor sport/camp, a family vacation and more, nothing is off limits! We ask EPP families to submit their story and tell us how we can help make your dealings with EPP easier.

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 28th, 2020 and our recipients will be selected on during Porphyria Awareness Week in April.

1. FAMILY SUBMISSION

This application must be submitted in its entirety and sent to Shadow Jumpers by March 28th 2020. Submission can be via email or by mail.

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 our recipients have been selected, the families will be notified by email. Additional calls or interviews may be conducted to help in the creation of the recipients' specific requests.

4. FIND YOUR SHADOW

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



Please print and complete all sides of this request form, sign and scan/email to craig@shadowjumpers.org or mail to

American Porphyria Foundation

Attention: Shadow Jumpers

4915 St. Elmo Avenue, Suite 200. Bethesda, Maryland 20814

CHILD'S DETAILS

Name _____

Child's Gender ☐ First ☐ Last
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 code _____ Phone _____

Email _____

FATHER / LEGAL GUARDIAN'S DETAILS

Name _____
First Last

DOB _____

Address (if different from child's) _____

City _____ State _____

Zip code _____ Phone _____

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.



SHADOW JUMPERS

The Sun is Overrated, Let Us Show You How

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

- The Child with EPP
- The family of the Child
- The request / moment to help the child/family
- 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 craig@shadowjumpers.org or

[American Porphyria Foundation](http://AmericanPorphyriaFoundation.org)

[Attention: Shadow Jumpers](mailto:Attention:ShadowJumpers)

[4915 St. Elmo Avenue, Suite 105, Bethesda, Maryland 20814](http://4915StElmoAvenueSuite105BethesdaMaryland20814)

- 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: __/__/____



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