



# Pachyonychia Congenita Project

*Fighting for a cure. Connecting & helping patients. Empowering research.*

## PC Advocates Training Session 1

# The Role of PC Advocates

## **PC Advocate** (public)

- Represent PC Project
  - Understand PC
    - Phenotype
    - Genotype
    - Impact and QofL
  - Understand PC Project
  - Understand IPCRR
  - Understand IPCC
  - Tell your story

## **Peer Coach** (patients)

- Help patients
  - Listen to them
  - Non-medical
  - Support
  - Build patient skills



# Welcome Volunteer

- Forms for volunteers
  - Application for Volunteers
  - Code of Conduct
  - Email release form



# **PACHYONYCHIA CONGENITA PROJECT VOLUNTEER APPLICATION**

## **CONTACT INFORMATION**

First Name:

Last Name:

Street 1:

Street 2:

City:

State:

Zip:

Home Phone:

Cell Phone:

## **E-MAIL**

Your email address will be used as our primary method for contacting you. We will NOT share your email address with any other entity.

Email address:

## **PLACEMENT PREFERENCES**

We have several volunteer opportunities available at PC Project. Please select the volunteer assignment choice that you would be interested in .

Peer Coaches

PC Advocates

PC Project Special Events

PC Fundraising Efforts

## **SKILLS & EXPERTISE**

In which of the areas below do you feel you have moderate to excellent skills/experience:

Clerical

Fundraising

Health Care Provider

Public Speaking

PR/Media Relations

Event Management

Social Media

Graphic Design

Writing/Editing

I understand that submitting this application form does not automatically register me as a Pachyonychia Congenita Project volunteer, and that there may be certain qualifications that I must meet, including the acceptance of the following volunteer policies and procedures before I may begin volunteering.

I agree



Pachyonychia Congenita Project

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2386 East Heritage Way, Suite B, Salt Lake City, UT 84109 | 1-801-401-6300 | [info@pachyonychia.org](mailto:info@pachyonychia.org) | [www.pachyonychia.org](http://www.pachyonychia.org)

# PC Project Volunteer Handbook

November 2015

# Volunteer Handbook

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# INTRODUCTION

Pachyonychia Congenita Project ("PC Project") appreciates those who wish to give of their time and talents for the benefit of the organization and its goals. The purpose of this Handbook is to explain daily operations, policies and procedures, and provide overall guidance for any individual wishing to volunteer for PC Project. Volunteers are expected to carry out their responsibilities to the best of their ability, in accordance with our Code of Conduct policy, while upholding PC Project's mission and adhering to these policies. Your role as a volunteer is critical to the mission of PC Project.

## OPERATING PRINCIPLES

Staff and volunteers of PC Project are guided by the following five main principles. We will always strive to:

- Make decisions according to mission and plans;
- Orientate ourselves toward measurable results in every endeavor;
- Communicate according to a standard of "compassionate honesty";
- Work to acknowledge and understand all points of view;
- Adhere to "gold standard" business principles.

## MISSION

PC Project's mission statement is "Fighting for a Cure. Connecting & Helping Patients. Empowering Research." To achieve this mission we strive to provide patient support and education, raise public awareness, support and catalyze research and improve health care practices. We envision a world where the lives of PC patients are improved and the burden of disease is greatly lessened or removed.

## WHO'S WHO AT PC PROJECT

PC Project is governed by a volunteer Board of Trustees and is advised by a volunteer Medical and Scientific Advisory Board (MSAB). A few individuals with subject expertise additionally may serve on specific advisory task forces. The Executive Director ensures advancement of PC Project's programmatic objectives, development and fundraising goals, and manages all staff and volunteer leaders.

PC Project has few paid staff to execute many of the programs and services we provide. We need volunteers to assist so that we can continue all services as the number of patients served increase and to continue to be good stewards of our donors' gifts. For more information on our staff and board, visit [www.pachyonychia.org](http://www.pachyonychia.org). Your time and talent, either on an ongoing or short-term basis, are needed to help us move forward.

# ENGAGEMENT GUIDELINES

## BECOMING A VOLUNTEER

Volunteers will be accepted through an application process. Volunteers are one of the most valuable resources at PC Project and as such are extended the right to meaningful duties, fair treatment and full participation and in exchange agree to perform their assigned duties to the best of their ability and remain loyal to the mission, goals and procedures of PC Project.

## **PLACEMENT AND USE OF SKILLS**

Volunteers will be matched to opportunities that recognize their talents, interests and availability for serving. If at any time a volunteer wishes to be reassigned or take on an additional project or role they can discuss their interest with PC Project staff.

To help keep PC Project running smoothly, it is important that volunteers complete their tasks on schedule and to monitor the amount of work to which one commits. If deadlines cannot be met, it is important to communicate that status with PC Project staff immediately and/or to seek out another volunteer to help with those responsibilities.

## **MANAGEMENT OF VOLUNTEERS**

Volunteers should work with staff to determine how they can most effectively serve. It is the responsibility of the volunteer to ask for assistance if needed and regularly report on progress to their staff leader, as well as to maintain a record of their own volunteer hours using the Track It Forward app. As appropriate, volunteers may receive evaluations to review their performance, allowing for both the volunteer and staff to suggest changes, seek suggestions and enhance the relationship between the volunteer and staff. Both staff and volunteer should establish an open line of communication to better enhance the functionality of the project and organization.

If for any reason a volunteer is unable or unwilling to carry out their commitment of service, she or he should notify their staff or volunteer leader as soon as possible. For volunteers serving in a principal role, advance notice (one month) of resignation is requested. If for any reason PC Project feels the need to terminate relations with a volunteer for the protection of the organization, it can do so at its sole discretion.

## **RECOGNITION & REWARDS**

PC Project seeks to honor and recognize its volunteers from time to time and in various ways. Volunteers shall not expect to receive any form of payment, including wages, food, clothing, shelter or other kinds of payment, for volunteer talents and services contributed to PC Project. PC Project encourages volunteers to help create and encourage a culture of mutual appreciation and gratitude for the hard work and contributions of fellow volunteers and encourages all volunteers to take the time to express thanks and appreciation to others when appropriate.

## **REPORTING VOLUNTEER HOURS**

PC Project asks that all volunteers keep a record of their volunteer hours using the Track It Forward app. This tracking allows PC Project to represent the impact of volunteers in helping us be good stewards of our dollars. In addition, many funders including individual donors, PC Project's, and corporations look more favorably on organizations that claim a large number of volunteers' contributing a large percentage of work hours.

## **LIABILITY**

PC Project is not financially or otherwise liable for injury or casualties that occur to anyone while serving as a volunteer for PC Project. Accordingly, volunteers agree to waive any claims against, indemnify, and hold harmless PC Project, its respective officers, directors, employees, sponsors, representatives and volunteers from any and all liability, including attorney fees, that may accrue on account of, or in any way growing out of, any and all property damage, personal injury, and/or economic loss as a result of or in any way related to or arising out of the volunteer's involvement with PC Project.

## **DISCRIMINATION**

PC Project does not discriminate against any applicant or volunteer with regard to hiring, retention, promotion, benefits or compensation because of race, national origin, ethnicity, citizenship, gender, age, marital status, creed, sexual orientation, disability, use of guide or support animals because of the blindness, deafness or physical handicap of the user or because the user is a handler or trainer of support or guide animals, gender identity, gender expression or any other characteristic protected by law. Similarly, PC Project does not discriminate against any client or applicant for services on any of the above criteria, and is committed to the promotion of diversity in all of its programs. No volunteer who makes a complaint in good faith or who participates in the investigation of a complaint will be subject to any form of retaliation on that basis.

## **SEXUAL HARASSMENT POLICY**

PC Project is committed to providing volunteers with an environment that is safe and productive and will not tolerate any form of sexual harassment or sexual misconduct among its employees and/or volunteers. Any volunteer who has a complaint or knowledge of sexual harassment or sexual misconduct should bring it to the immediate attention of PC Project staff, the Executive Director, or a member of the Board of Trustees. No volunteer who makes a complaint in good faith or who participates in the investigation of a complaint will be subject to any form of retaliation on that basis.

## **WHISTLEBLOWER POLICY**

PC Project is committed to providing volunteers with a mechanism to raise good faith concerns regarding suspected violations of law, to cooperate in any inquiry or investigation regarding illegal or dishonest activities that are violations of federal, state or local laws that include, but are not limited to billing for services not performed or for goods not delivered; other fraudulent financial reporting, etc. and to ensure against any form of retaliation for taking such action.

## **DISPUTE RESOLUTION**

If an issue or dispute should arise between volunteers, or between a volunteer or volunteers and staff, the parties involved should first communicate directly with one another in a respectful attempt to reach a mutual understanding. If the parties cannot reach a reasonable resolution, then a volunteer can request mediation from the Executive Director.

If a resolution cannot be reached even after such mediation, or if such mediation is unreasonable or impracticable (i.e. because a volunteer has a concern, complaint, or other issue the volunteer feels cannot be resolved by working with a staff member), then the volunteer is invited to contact a member of the Board of Trustees. PC Project website forums and social media are public and may not be used as a medium for airing conflicts, including boards that are protected from public view.

# **CONDUCT GUIDELINES**

## **REPRESENTING PC PROJECT**

All actions (i.e. speaking publicly, posting on-line, raising funds, spreading awareness) performed on behalf of PC Project must be carried out with a positive and professional customer service approach. It is likewise the responsibility of volunteers to regularly visit the website, read informational emails, to stay current and knowledgeable about PC Project activity and accomplishments.

Volunteers as representatives of PC Project will dress appropriately for the conditions and performance of their duties. Volunteers who work as support in an office situation will dress according to the code of that particular office. Individual volunteers will be informed of the dress standard for their duties at the time of assignment.

Professional, respectful and timely communication is expected of anybody representing PC Project whether in person, by email, phone or other communication form.

### **EMAIL POLICY**

A PC Project email (firstname.lastname@pachyonychia.org) will be created and maintained for individuals who:

- Have an active staff or volunteer leadership role (email accounts not used for 60 days will be deactivated and possibly deleted);
- Need to send email as a representative of PC Project;
- Have signed PC Project's Code of Conduct statement; and agree to send a bcc of any outgoing email to [info@pachyonychia.org](mailto:info@pachyonychia.org)
- Have a role that requires an individual email account. Expectations associated with maintaining a PC Project email account include:
  - a. Emails received will be responded to in a timely manner, usually within 48 hours. An out-of-office message should be set for emails that will be unmonitored for greater lengths of time;
  - b. Although generally less formal than other written communication, email is a business communication tool and users are obliged to use it in a responsible, effective, polite and lawful manner, recognizing that you and PC Project can be held liable for unlawful, libelous or defamatory emails;
- Email should not be used for personal matters, but rather for PC Project business only;
- All PC Project business will be conducted on your PC Project email account;
- Passwords should not be shared with others;
- Accounts not used for 60 days will be deactivated.

All email accounts and content maintained on our email systems are property of PC Project.

### **COMMUNICATION & TRANSPARENCY**

Volunteers shall recognize their work as being done as part of a larger team and therefore will keep the lines of communication open as appropriate within and among the various departments of the organization. Communication is important both to obtain information and feedback from volunteers and to share with them new information about PC Project. Email, teleconferences and webinars will be used, but volunteers should feel free to share where they see opportunities for growth, both for the organization and for themselves as volunteers.

As stated in our operating procedures (see page 3), our policy is one of "compassionate honesty." Our communications with one another shall be respectful, direct, and truthful with intent to resolve problems.

### **SOCIAL MEDIA POLICY**

PC Project considers social media sites (including, but not limited, to Facebook, Twitter, Instagram, Pinterest) to be an important extension of our communications strategy. Volunteer leaders may seek



approval to set up and maintain social media accounts specific to their event, or one may be created for them. Any and all such accounts are considered PC Project social media accounts for all purposes, and must adhere to the following rules:

1. All PC Project sites belong to PC Project and are considered an extension of the official methods of communication from PC Project. Volunteers must adhere to all conduct guidelines of branding usage in this Volunteer Handbook.
2. All PC Project branded communication channels should only be used to:
  - a. Fundraise for PC Project,
  - b. Raise awareness for PC Project,
  - c. Advertise and raise support for officially-sanctioned PC Project events,
  - d. Share information relevant to the mission of PC Project,
  - e. Volunteers cannot advertise fundraising events for organizations outside PC Project.
3. A member of PC Project staff must be a full-level admin on Facebook pages that contain any PC Project branded events or images.
4. Volunteers can share out links from other organizations meant for educational value such as shared by the staff communication team on the Official PC Project Site Facebook page. We encourage collaborations that drive greater awareness and education for this cause and that align with our goals and messages. When unsure of an outside article's relevance, accuracy or value, volunteers should consult with PC Project staff.
5. Volunteers operating PC Project social media accounts can (and should) advertise fundraisers that directly benefit PC Project.
6. If or when a volunteer leader of a PC Project-sanctioned event ceases to serve in that role, the volunteer should immediately remove him or herself from administrative rights of the page, or PC Project will remove the volunteer upon learning of their intent to not continue with the event. At their discretion, PC Project staff will maintain the account until a new volunteer leader is placed in the role, or delete the account. At all times the account remains the property of PC Project and shall not be used for any purpose other than those set forth in this section.
7. PC Project staff reserves the right to remove any content found objectionable on PC Project-branded social media sites.
8. Volunteers can be removed from their position on social media pages should they violate any of the communications policies outlined in this Volunteer Handbook.
9. Volunteers are encouraged to use their personal social media platforms to advocate for PC awareness, education and fundraising on behalf of PC Project.

### **ONLINE or WRITTEN COMMUNICATION**

All volunteers agree to communicate in writing with sensitivity, patience, and respect. Volunteers should remain conscious of the possibility for misinterpretation of tone and inference, especially in email. Volunteers agree to use clear and kind language when formulating messages.

### **PATIENT SUPPORT**

Volunteers will remain sensitive to the experiences of those who seek PC Project. Volunteers agree to become familiar with educational tools and materials that offer accurate information to patients in need and the general public provided to them (brochures, training and at [www.pachyonychia.org](http://www.pachyonychia.org)).

Volunteers are not permitted to offer medical advice of any kind, but can direct those in need to email PC Project or use the Contact Us at [www.pachyonychia.org](http://www.pachyonychia.org) to seek a medical consultation.



## **USE AND COPYRIGHT OF WEBSITE**

Volunteers will become familiar with PC Project website. Using PC Project's website for personal business promotion or other advertising is not permitted. PC Project reserves all rights and privileges to its logo, graphics, endorsement, and property, which cannot be used without consent of proper PC Project authorities.

## **CONDUCT**

A Code of Conduct agreement, which establishes an expectation of professional and respectful behavior, must be signed by volunteers working in an on-going role with PC Project. Volunteers represent PC Project in a highly public capacity and may be working with privileged information.

No volunteer should:

- 1) Authorize the use of the name, emblem, endorsement, services, or property of PC Project for the benefit or advantage of any person or organization, except in conformance with PC Project policy.
- 2) Accept or seek on behalf of any person, any financial advantage or gain of other than nominal value offered as a result of the volunteer's or employee's affiliation with PC Project, or knowingly take any action or make any statement intended to influence the conduct of PC Project in such a way as to confer any financial benefit on any person, corporation, or entity in which the individual has a significant interest or affiliation.
- 3) Publicly use any PC Project affiliation in connection with the promotion of positions on any issue not in conformity with the official position of PC Project.
- 4) Disclose or use any confidential PC Project information that is available solely as a result of the volunteer's affiliation with PC Project to any person not authorized to receive such information or use to the disadvantage of PC Project any such confidential information, without the express authorization of the Executive Director (see Confidentiality section for more detail.)
- 5) Operate or act in a manner that creates a conflict with the interests of PC Project and any organization in which the individual has a personal, business, or financial interest. The individual shall disclose such conflict of interest to PC Project's Executive Director, or a member of the Board of Directors, as applicable, upon becoming aware of it. Where required, the individual shall absent him or herself during deliberations, and shall refrain from participating in any decisions or voting in connection with the matter. (see Conflict of Interest section for more detail.)
- 6) Conduct themselves in any manner deemed inappropriate by the rule and guidelines provided by PC Project which includes, but is not limited to:
  - a. Theft or inappropriate removal or possession of PC Project's property or that of any volunteer, staff, agent or visitor, including failing to cooperate fully in any investigation of improper usage of PC Project property,
  - b. Volunteering under the influence of alcohol or illegal drugs, and/or illegal or unauthorized possession, distribution, sale, transfer, or use of alcohol or illegal drugs in the volunteer environment,
  - c. Creating a disturbance on PC Project premises, at sponsored activities or in areas which could jeopardize the safety of others, including any violation of any federal, state, or local safety or health law while acting as a volunteer of PC Project.

Volunteers are likewise asked to certify that the statements made in their volunteer application are true and correct and have been given voluntarily. PC Project may verify in whole or in part any information provided on the application. Information provided in the application will be kept confidential and will only be disclosed by PC Project if under a legal obligation to do so.



## **CONFLICT OF INTEREST**

PC Project wants all volunteers to fully recognize the importance of their duty to PC Project's constituents and supporters and the necessity to act in a manner that merits public trust and confidence. It is therefore necessary for volunteers to refrain from engaging in any transaction in which personal interests conflict, potentially conflict or appear to conflict with those of PC Project.

An actual or potential conflict of interest occurs when a volunteer is in a position to influence a decision that may result in a personal gain for the volunteer or for a relative of that volunteer as a result of PC Project's business dealings. For the purposes of this policy, a relative is a person who is related by blood or marriage, or whose relationship with the volunteer is similar to that of persons who are related by blood or marriage. Participation in any activity prohibited by this Policy can result in the termination of volunteer service.

While some conflict of interests are easily identifiable, PC Project requests that all volunteers be aware of examples of conflict of interest to promote the best working environment for PC Project. All public statements on behalf of PC Project should be made by a designated PC Project staff member.

The following list of "conflict of interests" is illustrative only and should not be regarded as all-inclusive:

- **Accepting Payment or Gifts:** No volunteer shall solicit for compensation of any kind (including gifts, cash, discounts, concessions, services or other similar item or benefits) for services rendered as part of his or her volunteer service. This includes payment for speaking engagements or for participation in workshops or similar activities. NOTE: If a person or organization wishes to make a charitable donation, volunteers are encouraged to conduct them to the proper donation channels, or if that is impossible, direct them to the project director so that the donation can be processed correctly.
- **Improper Influence:** Any volunteer or relative should not, when acting on his or her own behalf or when acting on behalf of another person, business or organization, attempt to influence PC Project's position on any issue, matter or transaction nor participate in any discussions pertaining to a related organization.
- **Confidential Information:** As explained in the Code of Conduct, inside, personal or sensitive information should not be used either for the purposes of gaining advantage for one's self, a relative, or another organization or for any other purpose not specifically approved for use by PC Project.
- **Political Activities:** Volunteers are encouraged to take an active interest and to participate in the political and governmental process. However, except for those authorized to act on behalf of PC Project concerning official affairs, volunteers participating do so as individuals and not as official representatives of PC Project. To avoid any inference of support or sponsorship by PC Project, a volunteer must never represent that his or her political donation, endorsement or other political activity was made or engaged in with the approval, or on behalf, of PC Project.

## **CONFIDENTIALITY**

Designated and authorized volunteers may be exposed to confidential information that is defined as inside, personal or sensitive information, and may include contact information, health information, or personal experience stories. The Code of Conduct signed by all volunteers upon completion of their volunteer application includes a confidentiality statement barring the sharing or disclosing of this information for any unauthorized purposes, including personal benefit.

# EVENT ORGANIZING GUIDELINES

We gratefully welcome those who wish to organize events that raise funds and awareness on behalf of PC Project, in accordance with our mission. Please review these guidelines if you are interested in hosting a special event or doing fundraising for PC Project.

It is our goal to empower, not limit, you in your desire to help this cause. Please use this information as a tool that leads you to a successful and rewarding experience on behalf of PC Project. If at any time you have questions or need more guidance, please contact PC Project staff.

## **PLANNING YOUR EVENT**

Because of PC Project's main mission of funding research and raising awareness about PC, most volunteers will in some way be a part of the fundraising process. Fundraising activities bring about significant tax, accounting, and liability issues and income must be documented according to state and federal requirements in order to prevent penalty to PC Project. It is crucial that our volunteers are aware of proper procedures when dealing with fundraising and for this reason we have included a few funding guidelines. To begin planning your fundraiser, check out the resources at [www.pachyonychia.org/donate\\_help.php](http://www.pachyonychia.org/donate_help.php). PC Project will add all approved events to the News and Events listings on our website. Announcements about your event will also be posted on the website.

## **REPRESENTING PC PROJECT**

Events and promotions must fit PC Project's mission and provide a favorable, non-controversial public image. PC Project name or logo can only be used with prior approval. Materials printed with PC Project name or logo, including letters, tickets, ads, banners, etc. that promote an event, or request contributions, need to be reviewed by the Executive Director and/or PC Project staff.

Every event is an opportunity to increase awareness about this rare genetic skin disorder. Official PC Project brochures, publications, awareness merchandise and the website address can be distributed at your event. These materials can be printed from the website or provided by PC Project staff to organizers according to the expected number of participants and funds to be raised. In addition, the DVD "What Is Pachyonychia Congenita?" can be shown to inspire and help spread accurate information to the event attendees.

Federal tax laws disallow third-party events from using PC Project sales tax-exemption number or Federal Employer Identification Numbers when purchasing any goods or services from suppliers/vendors. Bank accounts cannot be opened in the name of PC Project for any reason.

## **EVENT LIABILITY**

The volunteer organizer is responsible for filing for any necessary permits or insurance coverage needed to hold the local third-party fundraising event. PC Project cannot promise to pay or reimburse fees for such permits or coverage. PC Project cannot be held responsible in any way for casualties, thefts or accidents that occur at the event.

PC Project is not financially or otherwise liable for the promotion or staging of local events or projects. This includes ticket sales or other administrative aspects. The organizer must seek sponsorship, or have the means to cover up-front costs, such as ticket sales, promotion costs, or supplies.

## **FINANCES**

As a responsible steward of public funds, PC Project expects that a reasonable percentage of the gross revenues from fundraising events be directed to PC Project. The total cost to produce the event should not exceed the amount generated from the event. If event expenses are greater than the total collected, it is the organizer's responsibility to cover the additional expense.

The public should be informed of any net amounts that will actually be donated to PC Project. Potential donors must be informed that only portions of proceeds will be donated whenever less than 100% of the net income will be donated. The organizer is responsible for accounting documentation of revenues and expenses. All proceeds must be mailed to PC Project no later than 21 days following your event. Expenses for which reimbursement is sought must be pre-approved by PC Project staff utilizing the Final Budget Form before conducting your event, then submitted with accurate receipts and the Expense Reimbursement Report. Expense reimbursements will be delivered to you by PC Project no later than 21 days following submission of receipts and expense report. PC Project should be informed, in advance, of any companies approached for underwriting or contributions for the event, so as to coordinate, where necessary, national and regional corporate partnerships. No volunteer can take a commission for hosting an event.

## **SPONSORSHIPS**

If you plan to seek sponsorships and/or provide benefits to a business for their sponsorship, please contact PC Project at [info@pachyonychia.org](mailto:info@pachyonychia.org).

## **RECEIPTING AND TAX-DEDUCTIBILITY OF CHARITABLE DONATIONS TO 501(C)(3) ORGANIZATIONS**

Receipts must be distributed with accurate information, and income needs to be documented according to state and federal requirements and the nature of the donation in order to prevent penalty to PC Project. All donations or event registrations are accepted by checks made payable directly to PC Project or directly through PC Project's website by credit card (Visa, MasterCard, American Express or Discover).

### **Donation of Services & Products**

If goods and/or services are received in return for charitable donations (i.e. auction purchases, tokens of appreciation, giveaways, meals, beverages, etc.) the fair market value of those goods and/or services must be determined by the donor, in writing, and given to PC Project office for documentation.

### **Purchase of Donated Services & Products**

Supporters making a purchase of an item through a silent auction, live auction, raffle, etc., should contact their tax accountant to determine what, if anything, will be deducted from the total purchase amount to determine the tax- deductible portion of the donation (i.e. if event fee is \$100, but \$50 covers meal cost owed to hosting facility, only \$50 remains as the tax deductible donation to the charity).

### **Receipts for Charitable Donations**

PC Project's policy is to make every effort to acknowledge all donors with an official receipt outlining the tax deductible portion of that donation. A credit card transaction receipt is emailed directly for all donations made online to PC Project. All donations received in the mail by check over \$25 will have a receipt sent to the name appearing on the check received and that individual, corporation, PC Project, etc. will be the eligible party for tax benefits received as a result of the donation.



Cash donations should be converted to a cashier's check and subsequently donated in a single sum to PC Project. If the contact information of cash donors for receipting purposes is not included, only the individual whose name appears on the check will receive tax benefits for the donation. Donors contributing in this circumstance should be made aware that their gift will not be acknowledged as a tax-deductible donation to PC Project. If the donor of cash, property or in-kind donations wishes to receive tax documentation, the organizer must provide the detailed information listed below:

- Donor's complete name and address
- Date and amount of the contribution
- Whether the contribution was cash, in-kind services or property (non-cash)
- If applicable, description of the type of property and a good faith estimate of the fair market value
- If applicable, detailed description of any goods and services provided in exchange for the contribution

### **SUPPORT FROM PC PROJECT STAFF**

PC Project staff members are available to offer general advice on event or project planning along with tips for your specific type of event, implement income documentation procedures, as well to have educational and awareness materials provided for your event where appropriate. If you are seeking sponsors, PC Project can provide sample sponsorship letters and benefit ladders.



## QUOTES

"Never doubt that a small group of thoughtful committed citizens can change the world; indeed, it's the only thing that ever has." ~ Margaret Mead

"I am only one, but still I am one.  
I cannot do everything, but still I can do something;  
and because I cannot do everything,  
I will not refuse to do something that I can do." ~ Helen Keller

"If not you, who?  
If not now, when?"

"Character cannot be developed in ease and quiet.  
Only through experiences of trial and suffering can  
the soul be strengthened, vision cleared, ambition inspired  
and success achieved." ~ Helen Keller

"We can do no great things -  
only small things with great love."  
~ Mother Teresa



# Pachyonychia Congenita Project

*Fighting for a cure. Connecting & helping patients. Empowering research.*

2386 East Heritage Way, Suite B, Salt Lake City, UT 84109 | 1-801-401-6300 | info@pachyonychia.org | www.pachyonychia.org

## Acknowledgement & Receipt

I \_\_\_\_\_, acknowledge that I have received a copy of the PC Project Volunteer Handbook.

I understand that this manual contains information regarding PC Project's rules, regulations and provides overall guidance for any individual wishing to volunteer for PC Project.

I acknowledge that I have read, understood and will follow PC Project's policies.

I also understand that PC Project may revise, supplement or rescind policies, procedures or guidance described in the manual, with or without notice.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date



# Pachyonychia Congenita Project

*Fighting for a cure. Connecting & helping patients. Empowering research.*

2386 East Heritage Way, Suite B, Salt Lake City, UT 84109 | 1-801-401-6300 | info@pachyonychia.org | www.pachyonychia.org

## CODE OF CONDUCT

I understand and agree that submitting this application form does not automatically register me as a PC Project volunteer, and that there may be certain qualifications I must meet, including the acceptance of the following established volunteer policies and procedures before I may begin volunteering:

I desire to serve as a volunteer with PC Project (the "PC Project") and help further its stated mission.

As a volunteer, I understand that I may be exposed to confidential information that is defined as inside, personal or sensitive information, and may include contact information, health information, or personal experience stories. By agreeing to this Code of Conduct, I am prohibited from sharing or disclosing this information for any unauthorized purpose, including personal benefit.

In all situations in which PC Project is involved, I promise to conduct myself according to the standards set forth in PC Project Volunteer Handbook (available at [www.pachyonychia.org](http://www.pachyonychia.org)) and I understand that it is my responsibility as a volunteer to remain professional, respectful and discreet at all times.

I acknowledge that I have access to the electronic version of the Volunteer Handbook and understand the contents of the Volunteer Handbook. I have now, and in the future, the opportunity to ask and receive answers to any questions I have about the contents of the Volunteer Handbook.

I also understand that I must disclose any of my outside interests that may be in conflict or competition with the interests of PC Project or that stand to benefit from my involvement therewith, and then refrain from participating in any discussions pertaining to those conflicts.

I understand that PC Project is not financially or otherwise liable for injury or casualties that occur to anyone while serving as a volunteer for PC Project.

I hereby grant PC Project specific permission to reproduce, publish, circulate, copyright, or otherwise use any and all photographs and/ or videotape of me and/or my family taken at any volunteer event, for use by PC Project.

### CODE OF CONDUCT CERTIFICATION AND DISCLOSURE

By signed below, I certify that I have read and understand PC Project's Code of Conduct, I have the opportunity to read the Volunteer Handbook at any time, and I agree to comply with the terms therein, as well as applicable laws that impact PC Project. I also understand that should I not maintain the conduct outlined above, PC Project reserves the right to terminate my voluntary position immediately. I also have the right to step down from my volunteer position at any time. I consent to any and all background checks, tests and verifications PC Projects deems are necessary for me to become and/or maintain being a Volunteer with the PC Project.

\_\_\_\_\_ I agree dated \_\_\_\_\_ by \_\_\_\_\_  
Signature

# Advocate Topics for Sessions

- Topics for next sessions
  - Session 2
    - Understand Pachyonychia Congenita
    - Understand PC Project
  - Session 3
    - Understand IPCRR
    - Understand IPCC
  - Session 4
    - Telling Your Story (2 minutes; 300 words)
  - Session 5
    - In-person training