

National Volunteer Leadership Conference

# KEYS TO A CURE

## Psoriasis One to One

Volunteer Leader Workshop

San Antonio, Texas

August 15, 2009



# Psoriasis One to One

National Volunteer Leadership Conference

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## Program Overview



# KEYS TO A CURE

Psoriasis One to One program is a new volunteer opportunity for people who want to:

- Share their experience and knowledge of psoriasis and/or psoriatic arthritis with others
- Provide emotional and motivational support
- Help motivate people to participate in Psoriasis Foundation activities

The primary goal for the Psoriasis One to One program is to:

- Provide assistance to newly diagnosed patients (psoriasis and/or psoriatic arthritis) or patients who have moderate to severe psoriasis and would like to know about psoriasis resources and connect with others who have the disease

The  
secondary  
goal is to:

- Encourage psoriasis patients and their families and friends to get involved with the Psoriasis Foundation
- For example, join the PAN network, become a member, attend Capitol Hill Day, donate blood to the BioBank, attend a local walk, form a walk team, become a Psoriasis Mentor



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One to One Mentors

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This program can't work without volunteers – this is why we need **YOU**

- We need dedicated volunteers who will serve as psoriasis mentors, and be available to reach out to patients who need someone to connect with
- This connection can be done over the phone, e-mail or in person.

Who makes  
a good  
mentor?

- Has psoriasis and/or psoriatic arthritis
- Is in current treatment for his/her disease or is in remission
- Has a good relationship with his/her dermatologist and primary health care provider (PHP)

Who makes  
a good  
mentor?

- Maintains a healthy lifestyle and understands the importance of managing overall health
- Enjoys connecting with others and is comfortable reaching out to people he/she doesn't know
- Participates in other Foundation programs (BioBank, Walks, Advocacy, message board, etc.)

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Parents with a child or children with psoriasis and/or psoriatic arthritis

- His/her child should be in treatment and see a regular dermatologist/rheumatologist
- Encourages his/her child to talk openly about the disease
- Helps their child understand the life-long implications of the disease
- Comfortable engaging with families from diverse backgrounds
- Has the time to devote to help other parents



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## Roles and Responsibilities of Mentors

Once a patient elects to be connected with a mentor

- The mentor will be contacted by the Foundation and given the patient's contact information
- The mentor will need to make contact with the patient within two to three days of receiving the assignment from Foundation
- Track communication with patient
- Provide patient with needed information and materials, and keep communication and dialogue as long as necessary and appropriate

Remember  
the secondary  
goal, this is  
the long-term  
goal

- Maintain ongoing contact with the person and track their progress and to cultivate a long-term relationship with the Psoriasis Foundation
- Invite them to participate in other Foundation programs or events. For example:
  - Local Walk to Cure Psoriasis
  - Foundation member
  - Message board
  - Psoriasis Action Network (PAN)



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Psoriasis Mentor Training

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## Overview of the Psoriasis Foundation

- Mission of the Psoriasis Foundation
- History of the Foundation
- Overview of programs
- Educational resources
- Local resources

## Basic disease education

- Scope of the diseases (psoriasis and psoriatic arthritis)
- Common triggers
- Related illnesses (co-morbidities)
- Burden of disease (emotional and physical)
- Myths and misconceptions

Basic  
treatment  
education

- Available approved treatments on the market
- Tips how to find the right doctor
- Importance of compliance with a treatment regimen
- Establish a good relationship with a PHP
- Managing overall health
- No medical advice will be given by any volunteers

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## Insurance access training

- General health care policies and guidelines
- Ways to access detailed health insurance information
- How to file a basic appeal
- How to file for disability
- How to recognize discrimination

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## Emotional support

- How to appropriately respond to distressed patients
- Provide support and encouragement
- Recognize the need for professional help

Emotional  
support  
training

Sept. 17 at 9 a.m.  
Pacific Time via  
WebEx



Julie Nelligan, Ph.D.  
Licensed psychologist

Dr. Nelligan is a licensed psychologist in Portland Oregon who practices cognitive-behavioral therapy. Many of her patients live with chronic diseases like psoriasis and psoriatic arthritis. She will provide us with techniques how to best work with patients' emotional needs.

## Involvement – the three E's

- Educate others about the importance of supporting our research efforts through advocacy and fundraising
- Encourage others to become members of the Foundation
- Excite others about Foundation activities

## Program oversight

- The Psoriasis Foundation has formed an education sub-committee to make recommendations and provide their expertise.
- This committee members are
  - Lakshi Aldredge, N.P., VA Portland, Ore.
  - Allyson DeLorenzo, Member, Board of Trustees
  - Nicora Gardner, M.S.W., Health Education Manager
  - Krista Kellogg, Member, Board of Trustees
  - Olga Tuttle, Sr. Manager, Education and Outreach
  - Stephan Weiss, M.D., Dermatologist



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Commitment From  
Psoriasis Mentors

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Before you begin mentoring, you will need to complete the following:

- Complete and sign all appropriate paperwork
- Complete phone interview with Foundation staff
- Attend WebEx basic training(s)
- Become a current member of the Psoriasis Foundation, if you are not already

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Before you begin mentoring, you will need to complete the following:

- Plan to participate in local Walk for to Cure Psoriasis event if there is one in your local area
- Agree to at least one year of psoriasis mentoring after you are trained



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Partnering With  
Medical Professionals

## Partnering with medical offices

- The Foundation will partner with dermatology offices who will identify patients to the One to One program
- These offices will receive PACKS (Psoriasis Action and Connection Kit) to give out to patients. Each kit contains a card which is to be completed by the patient if they wish to be contacted by a mentor.
- Patients can opt out of a mentor and still receive the kit

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This card will be mailed to NPF by the medical office

## *Get connected—get support—get involved*

Name \_\_\_\_\_

Address \_\_\_\_\_

Phone \_\_\_\_\_

E-mail \_\_\_\_\_

*You will be contacted by a local **psoriasis mentor** who can provide you with information, support and opportunities to get involved in the local psoriasis community.*

*If you would prefer to not be contacted, please check the box below.*

Please do not have a psoriasis mentor contact me.

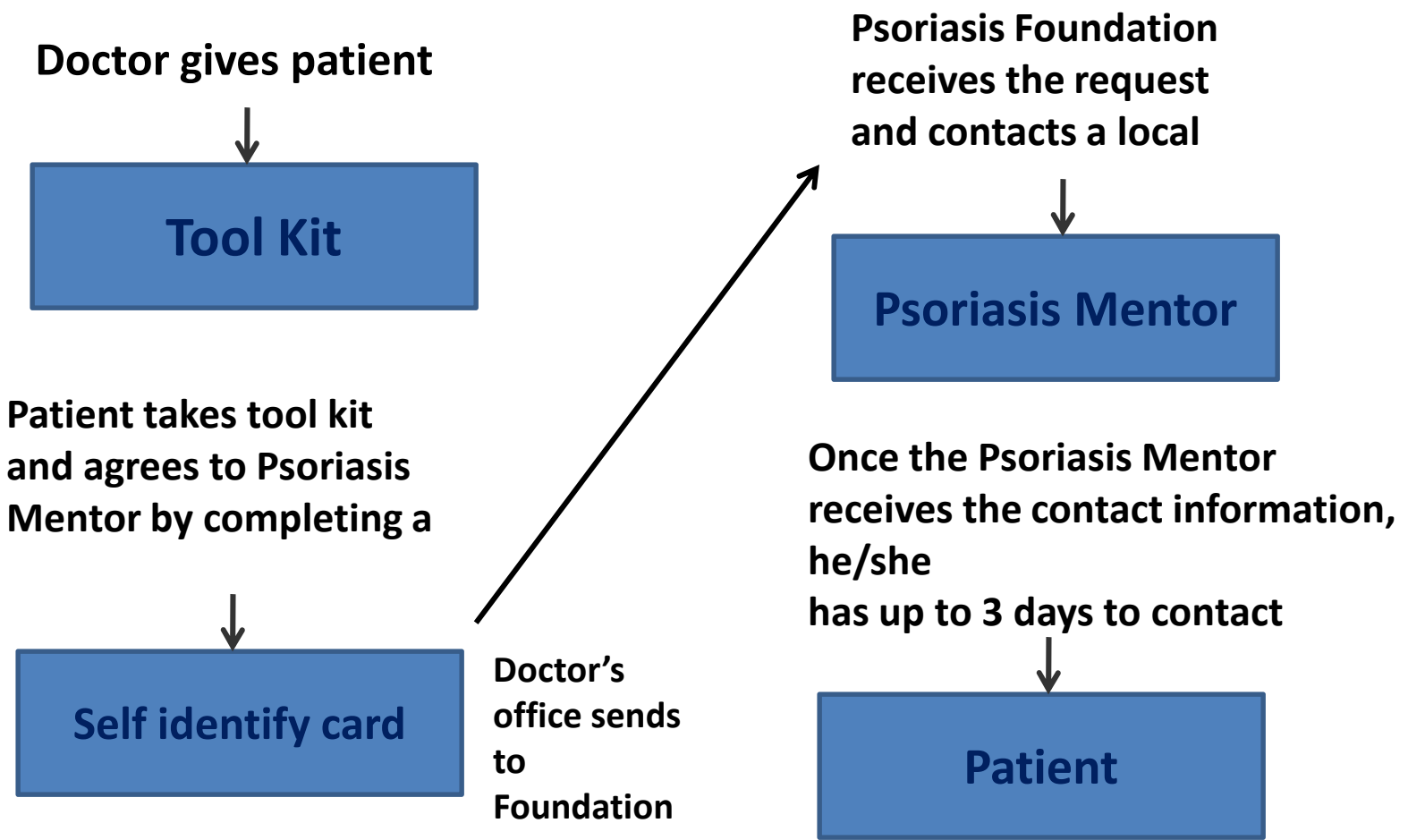


Join the National Psoriasis Foundation in finding a cure for psoriasis and psoriatic arthritis

**National Psoriasis Foundation**

**Please note: This is not the final design of the card**

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**PACK: Psoriasis Action  
and Connection Kit**

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- **PACK contents**

- Overview of ps/psa booklet
- OTC product guide
- *Psoriasis Advance* magazine
- Foundation brochure
- Flyer with local contacts & resources
- Postcard/window stickers to promote P.A.N.

*Product samples from our sponsor*



*PACK bag*



*Lotion applicator*

**Need to talk?**

Visit our message boards at [www.psoriasis.org](http://www.psoriasis.org)

*Refrigerator magnet*

*Dry cloth to control itching*





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One to One Support

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Support from a mentor can include:

- Emotional support – patients will need someone who will listen and understand what they are going through, help break feelings of isolation
- Information - what they should expect from their doctor and treatment

Support from a mentor can include:

- Assistance with information on insurance coverage for psoriasis treatments, especially for biologics
- Understanding of frustration with flares and treatment failures
- Discussion about pregnancy and psoriasis, treatments during pregnancy
- Share the joy of treatment successes, and encouragement and hope for a cure

Support from a mentor for parents can include:

- Emotional support – share the feelings of having a child or children with the disease, and possible guilt of heredity
- Resources – how to find a good pediatric dermatologist
- Assistance with information on insurance coverage for psoriasis treatments, especially for biologics

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Support from a mentor for parents can include:

- Understanding of treatment options for children, weighing the risk and benefits
- Encourage parents to have their children be open about their disease, and help educate other children

Support from a mentor can include:

- Long term resource – after initial contact and help is received, the mentor can be contacted from the patient or parent whenever additional assistance is needed
- Foundation updates – mentors will periodically check-in with their mentees, and give them updates on Foundation events, programs, etc.

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Support from a mentor can include:

- Foundation involvement – mentors will also encourage and excite mentees to participate in local events such as the Walk to Cure Psoriasis. They mentors will provide the various volunteer opportunities and ways to get involved.



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What Next?

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Key markets  
for program  
roll out with  
the PACKs

- Chicago
- Los Angeles
- New York City and Long Island
- Philadelphia
- San Diego
- San Francisco

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Each key market will need:

- 10 to 15 dermatology offices to participate
- 3 to 5 committed volunteer mentors

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Time frame  
for program  
role out

- June through September – contact dermatology offices
- August – National Volunteer Leadership Conference – introduce program to volunteers

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Time frame  
for program  
role out

- August through September – recruit and train volunteer mentors
- October – send kits to dermatology offices, start referring patients to One to One program
- January/February – first round of program evaluations

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## Recruitment plan for volunteers

- Word of mouth – volunteer to volunteer
- Contact members in key markets via e-mail, phone
- Recommendations from dermatology offices

## Scheduled training dates

- 9/3 – Dr. Julie Nelligan will meet with Foundation staff to discuss her recommendations for the mental health portion of the training (for Foundation staff and education sub-committee only)
- 9/17 – First training for volunteers via WebEx
- Other training dates (tentative) – 9/23, 9/29 and 10/3

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**Questions?**



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**Please remember to complete an  
evaluation on our Web site:**

**[www.psoriasis.org/netcommunity/events\\_conf](http://www.psoriasis.org/netcommunity/events_conf)**