Dermatology Congress of Zurich

Mum & Molly Spotlight PRP

A Special Report from Bill McCue, PRP Alliance

The Canton of Zürich has a population of over 1.4 million. It is divided into 12 districts and 171 municipalities.

The largest municipality is Zürich with an estimated population of 383,706.

The City of Zürich is also the home of a five-year-old girl with blond hair, pigtails and, according to her Mum, "eyes the color of a magical pond in the land of the fairies".

For those who look closely they will see a mixture of brown-green-blue. She also has Type III, classic *juvenile pityriasis rubra pilaris*.

With a prevalence rate of one in 400,000, Molly's PRP appeared out of no where. And that is where this story begins. A story about a mother, her daughter and PRP-savvy dermatologists who continually enlighten their peers. It is a story of hope for children and adults yet to be diagnosed with PRP.

A little girl. One mum. Many doctors. On a journey together.

Peeling hands, a red spot and a plea for help

In August 2013, Christine Günther first noticed that her daughter's hands were peeling. When a red spot appeared on the Molly's back in September, an appointment was scheduled with a local dermatologist. With an unconfirmed diagnosis of *psoriasis* or *neurodermatitis*. Mum and Molly were referred to University Children's Hospital Zurich. On October 16, 2013, Dr. Lisa Weibel, Head of Pediatric Dermatology, made the official diagnosis: *pityriasis rubra pilaris*.

On November 5, 2013, Christine, Molly's Mum, posted the following message to the PRP Support Group:

> *"Hi—Is anybody out there who can help and support us with information or personal experiences about the topic 'Children with PRP'? Our four-year-old daughter has had PRP for a couple of months and we feel a bit lost with this diagnosis! We live in Switzerland and are grateful for any help written in German or English! Thanks a lot, Christine.*

It was the word "lost" and the exclamation point that made me take notice. Unfortunately Christine's appeal came the day before the formal start of the 2014 PRP Worldwide Census. Back then I had only six PRPers with an onset age between three and eight. Today the PRP Community database has 49 PRPers with the same onset date parameters.

I was confident, however that the PRP Community would reach out to her. An email months later reaffirmed that confidence.

> *Bill—*
> *I've received many emails from parents of PRPers. Clarissa from USA who has a daughter Molly's age. Another American, Sonja, who lives with her little PRP son in Italy. She wrote me a very helpful and very long email. There was also a Mum of a boy from Sweden and so many others.*

Five-year-old Molly Gunther is ready for another day on her journey to remission.

Another plea from Switzerland

On May 5, 2014, six months to the day after Christine's frantic plea to the PRP Community, I received the following email.:

> *Bill—*
> *The University Children Hospital of Zürich has asked me today if Molly and I can participate in their annual meeting of dermatologists of the Canton of Zürich. Molly would be "showcased". During a 90-minute workshop dermatologists would form small groups and meet with us. For most of these dermatologists it will be the first and last time they will actually see an "active" PRPer.*

If that was where her email ended I would have offered to send her comments about Grand Rounds I had harvested from the PRP Support Group archives going back 17 years. But Christine had something else in mind.

> *I would like to give everyone a flyer with links to the two PRP support groups, the PRP Alliance and the PRP Community newsletter. I'm sure they will take it because you can't refuse a flyer from a Mum. Can you? Maybe we can help other PRPers or there will be other opportunities. What I need is your help! Are you interested in helping me creating such a flyer?—Christine*

Was this the same distraught Mum of early November? I had just received an email from a bona fide PRP Community advocate.

Over the next seven weeks the flyer evolved from a trifold brochure to a Special Swiss Edition of the PRP Community newsletter. PRPer ***Tierney Ratti*** (Virginia Beach, VA) and Surrogate ***Pat Batty*** (St. Thomas, Ontario, Canada) helped with proofreading and copyediting. And Christine, with English as a second language, found errors we all missed.

Each one different.

Each one special.

Each one different. Each one special. The logo and tagline of the PRP Alliance underscores how each PRPer has his or her own unique version of PRP. The salmon snowflake was designed by graphic designer Emily Cabrian, San Diego, CA.

Christine Günther had cooperation at every turn. When dermatologists embrace a spirit of teamwork and cooperation, dermatologists are enlightened and the PRP Community reap the benefits.

L-R: Dr. Regulä Wälchli, Christine Günther and Dr. Martin Theiler

The Dermatology Congress of Zürich

Dr. Antonio Cozzio, Head of the dermatology of University Hospital Zurich ensures that Molly is treated with care and respect

The official name of the event is the Annual Meeting of the Dermatologists of the Canton of Zurich. From June 25 through 28, more than 100 dermatologists from assemble to be enlightened. Both parts takes place at the University Hospital (Dermatology) not at the Children's University Hospital.

Christine and Molly were scheduled for the June 26th Workshop: "Dermato-Paediatric Live Cases" held at University Hospital in the Dermatology Clinic. The workshop had two parts:

Part 1—The Quiz of events:

Five patients and their parents are assigned an examination room. Dermatologists were asked to guess what kind of skin disease the patient could have based on clinical observations and questions directed at the patient, his/her parents and the dermatologist who treats the patient.

Christine was quick to note that it was relaxed atmosphere!. The patients were treated with respect. Our Molly felt never like an animal in zoo. She played and was relaxed throughout "The Quiz". Specifically:

- Interested dermatologists visited the invited cases in small groups and asked their questions and looked at Molly's skin.
- The ones who touched her skin asked permission.
- In the end every patient received a gift. "A very kind and unexpected gesture," Christine added.

Part 2—Feedback & Discussion:

While Molly was entertained by her father, Christine moved from the examination room and into a large lecture hall. They could have gone home, but there was work to be done. Remember, Mum is a PRP Community advocate. During this part every case was explained by the dermatologist who treats the patient. Dr. Regula Wälchli discussed the diagnosis and October to the present. Participating dermatologists could ask questions hear the feedback from fellow dermatologists.

While Dr. Jean-Philippe Görög, Bern, Switzerland examines the Molly's foot as she draws flowers, seemingly unaware that she is in a clinical spotlight.

Observations of a Mum

- “One special thought came in my mind while I was sitting there and listening. We are not alone with PRP-like nightmare. I saw parents of children with mastozytose, Juvenile xanthogranuloma, juvenile lichen planus and blepharochalasis. We all live a nightmare.”
- “I was the only parent who had a little speech and I felt, and still feel, a little bit sorry for the other parents and hope they have an “Alliance’ to support them.”
- “I had the impression that the dermatologists were quite impressed about the PRP Alliance because it is different to other support groups.“
- “After Regula Wälchli introduced me and told them why I am there my very personal subjective impression was that they thought first “oh no, not a mum who starts to cry and whine how horrible PRP is!”. It was a surprise for them to see how professional the PRP Alliance worked.“
- “Together with Dr. Wälchli we stood next to the exit and handed out the Special Swiss Edition of the PRP Community newsletter. They had no chance to leave without it! (My husband printed them the night before in his office between midnight and 1 o’clock.)”
- “I hoped there were dermatologists returning home by train or riding in a colleague’s car reading the Special Swiss Edition of the PRP Community newsletter.”
- “Dr. Wälchli was great! She supported me, Molly and the PRP Alliance the whole morning. She had a shorter speech so there was enough time for me.”
- Even Herr Theiler supported the PRP Alliance while leading the Workshop.
- It was a Great Day for PRP sufferers and the PRP Alliance!

Sage advice from Molly’s Mum

Be prepared to keep your young child occupied. Toys, a favorite stuffed animal, markers and paper. Load up with whatever you can carry. And when they get super active, try the “Electronic Grannie” —a smart phone with a Miffy der Film video. Works for Molly.

More sage advice from Molly’s Mum

When a child is in a clinical spotlight, be careful with what we call “Intimsphäre”. Don't give her/him the feeling of being naked.

Take their favourite swimwear with you and pretend do be at a beach party! The less you show, the better. The dermatologists were not hampered in their clinical observations in any way by Molly’s swimsuit.

PRP Ambassador Speaks to Swiss Dermatologists

The following speech was delivered by Christine Gunther as the newly appointed PRP Ambassador to Switzerland.

When sufferers of *pityriasis rubra pilaris* communicate with one another, "nightmare" is a word that you will read or hear frequently. I often use it when trying to explain how life feels after a diagnosis of PRP is rendered.

As parents of a five-year-old daughter, we were shocked how fast PRP spread over her entire body. We felt absolutely lost. There seemed to be no defense against this horrible disease.

Thankfully we found an ally. "Our Team" at the Children's University Hospital Zurich was, and still is, a great help. We also found the PRP Alliance and our feeling of powerlessness went away.

The PRP Alliance is a gathering of PRPers and surrogates worldwide. We are dedicated to the enlightenment of fellow PRPers and dermatologists. Our goal is to use our intimate understanding of *pityriasis rubra pilaris* to improve the diagnosis and treatment. We have a very rare skin disease that must be dragged into the spotlight where it can be understood by dermatologists who can make a difference.

To learn about the PRP Community and the PRP Alliance, go to www.prpAlliance.com and immediately click the PRP Community Newsletter Archives for back issues and the Special Swiss Edition specially written for this annual meeting

- PRP Worldwide Census where data is gathered from PRPers by PRPers and shared with dermatologists
- Registry of PRP-Savvy Dermatologists to support both PRPers and dermatologists
- PRP Meet & Greet where the PRP Alliance helps coordinate face-to-face gatherings
- PRP Facebook Support Group where PRPers can get in touch with each other and support each other
- Status of PRP Research like the Thomas Jefferson University PRP research project in Philadelphia

Please feel free to take a printed sample with you.

I ask each of you — please support PRPers and their families as they journey from onset to remission. Help PRP sufferers wake up from their personal nightmare.

And please share the Special "Swiss" Edition of the PRP Community newsletter with any patient being treated for PRP. Most importantly, tell them about the PRP Alliance.

One day, perhaps, you may write an article about pityriasis rubra pilaris that helps educate PRPers and fellow dermatologists.

Thank you very much for your interest. And once again, special thanks to "our team" at the Children's University Hospital Zurich. They have enthusiastically supported the PRP Alliance and made it possible to share this information with all of you today.

Thank you.

Epilogue

Molly Gunther is back home trying to get better. We hope she is among those to go into remission within a year or two. Christine as not accepted an invitation to join the PRP Alliance Executive Advisory Board, but to help enlighten Switzerland as a PRP Community Ambassador. On November 5, 20113 she was pleading for help. Six months later she gave a speech in a lecture hall to 50 dermatologists and calling for them to

- Support PRPers and their families as they journey from onset to remission.
- Share the Special "Swiss" Edition of the PRP Community newsletter with any patient being treated for PRP.
- Tell PRPers, surrogates and dermatologists about the PRP Alliance.

Molly is lucky to have her Mum. The PRP Community is lucky to have her as well.

06/23/2014—Message from:
Dr. Stephan Nobbe
Frauenfeld, USZ

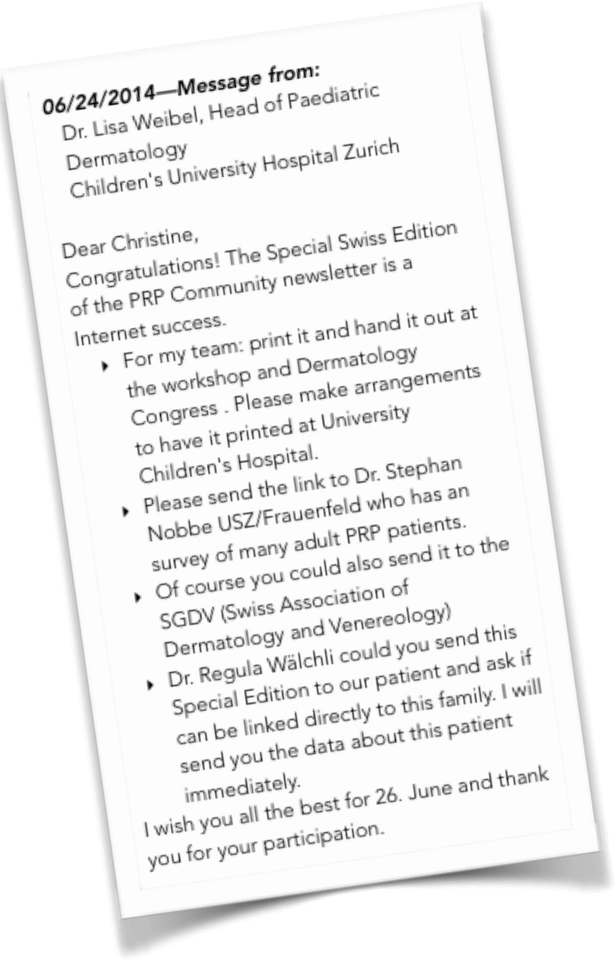
Dear Mrs Gunther

I would like to congratulate too for you work!

Two of my PRP patients have asked me during the last years, if something like a "PRP-Community" exists - a platform where you can share experiences. It is nice that something like this exists now!

During the last 4 years I have treated 3 adult PRP-patients until (full) remission. I think that the 31-year old woman form Aarau who is mentioned in the Special Swiss Edition of thePRPCommunity newsletter Issue is probably one of my patients.

At the University Hospital of Zurich I lead a register about 10 RPR patients Type 1. With the documentation of these cases and the documentation of the effect/outcome (sorry I don't know the right expression!) of the different therapies we hope to get new insights about the disease running and therapy options for PRPI wish you with your project good luck and hope that many PRP patients can benefit from it.

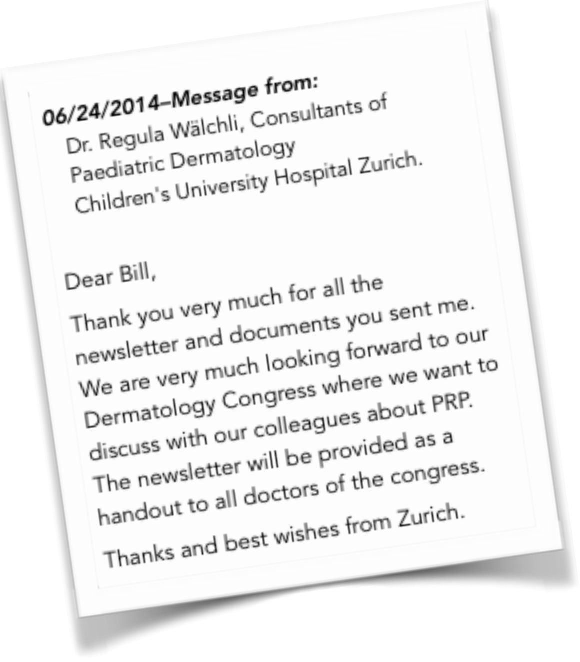


06/24/2014—Message from:
Dr. Lisa Weibel, Head of Paediatric Dermatology
Children's University Hospital Zurich

Dear Christine,
Congratulations! The Special Swiss Edition of the PRP Community newsletter is a Internet success.

- For my team: print it and hand it out at the workshop and Dermatology Congress . Please make arrangements to have it printed at University Children's Hospital.
- Please send the link to Dr. Stephan Nobbe USZ/Frauenfeld who has an survey of many adult PRP patients.
- Of course you could also send it to the SGDV (Swiss Association of Dermatology and Venereology)
- Dr. Regula Wälchli could you send this Special Edition to our patient and ask if can be linked directly to this family. I will send you the data about this patient immediately.

I wish you all the best for 26. June and thank you for your participation.



06/24/2014–Message from:
Dr. Regula Wälchli, Consultants of Paediatric Dermatology
Children's University Hospital Zurich.

Dear Bill,

Thank you very much for all the newsletter and documents you sent me. We are very much looking forward to our Dermatology Congress where we want to discuss with our colleagues about PRP. The newsletter will be provided as a handout to all doctors of the congress.

Thanks and best wishes from Zurich.