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Areata  
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Universalis

research awareness information support embrace



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# PRESIDENT'S WELCOME

How is everyone coping with the recent changes in their lives?

Have you seen our new Coping Techniques infographic? ([Web site link here](#)) and don't forget we have our Coping with Alopecia Areata Brochure, [here](#).

2020 is turning out to be a little different than we imagined when we welcomed in the year, and although monetary donations have slowed, our support grows stronger with two new committee members joining, bringing our team to 20.

In 2010 AAAF started with a mission:

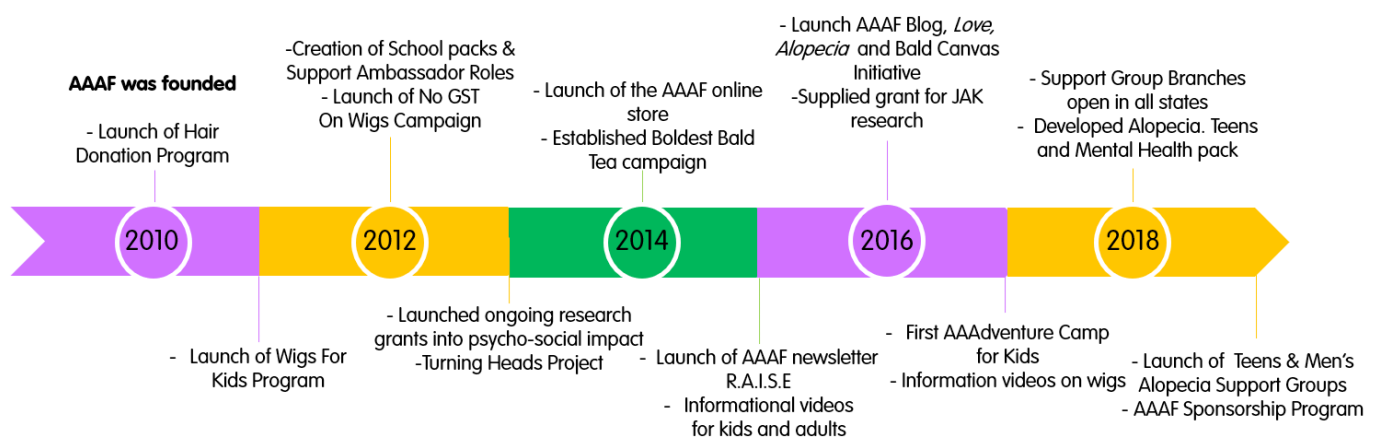
- **Support:** provide support to those with all forms of Alopecia Areata, and their families;
- **Awareness:** inform the public and create awareness of Alopecia Areata;
- **Research:** to support research into a cure or acceptable treatment for Alopecia Areata

Every one of those 10 years AAAF has run programs for the individual, for the family members, for peers and for the wider community, to ensure that you are not alone in your journey from the beginning to the end and sometimes back to the beginning. We have continued to provide opportunities for you to have a voice, and AAAF encapsulate both medical and psychological aspects into our programs and support models.

Whether you are new to AAAF or have been with AAAF for the ten years, we remain to be the only national support group for those with medical hair loss.

It has been a fast moving 10 years, with a dedicated team proven to get a huge amount of deliverables executed with limited resources through a volunteer team. I couldn't be prouder of the wonderful achievements the team at AAAF has accomplished.

Below is a time line of a handful of AAAF achievements:



# MEET OUR COMMITTEE

## SUPPORT AMBASSADOR - WA Clara

2010 Perth, Western Australia

My 15th Birthday



I went to tie up my hair, and as I was running my fingers through it, I felt a patch and immediately had a break down, in the middle of my party. My mum scurried me away to see what was the matter, and there it was, my first tiny patch, no bigger than a 5 cent piece. I was bawling my eyes out and my mum just said, okay, doctors tomorrow, stop stressing, its your birthday, so I continued with my party pretending nothing was wrong, but feeling like everything was.

Of course the next day, the doctor told us it was Alopecia Areata, and neither of us knew what that was, so when we got home, my absolutely distraught mother jumped on the computer and Googled and Googled to find as much information as she could. She didn't find much, but she did find the AAAF, so much like the foundation, I will also have my 10 year alopeciaversary this year.

Honestly I think my mum took it worse than I did at the time, when two days later she took me to the hairdresser to flip my side part over to the other side, and cut my long hair to a short bob, so no one would notice the patch. It worked... for about two days. It just kept falling out. Clumps in the shower. Clumps in my bed. The worst day was when I was at a live TV event sitting in the audience, and I got up and my friend looked at me and said, Clara look at the chair. It was covered in my hair. I sort of just shrugged it off and stuffed all the hair into my backpack and we went along with our day. That week I took a note to school asking all my teachers permission to wear a head covering, to hide the patch and to let me sit at the back of the class where possible, and everyone was super accommodating and kind about it. By Thursday night I had felt like I'd lost so much control of my situation and I needed to take some back, and I sat down with mum and wrote a new note.

Continued Over

# MEET OUR COMMITTEE

## -Continued

Basically what it said was:

Clara has Alopecia Areata and she has decided that she is going to shave her head this weekend, please let her stand up in all of her classes to explain what is happening, what it is, and why she will be coming to school on Monday looking a little different. She doesn't want to show up and be bombarded with questions, so she would like to take control of the situation and allow her classmates to ask their questions now.

There were a lot of tears. From me, the teachers, my family and my classmates, but I finally felt like I had a bit of control back.

Flash forward to now, I'm 25, and I have an almost full head of hair. I've lost my hair almost completely, 4 times, and I still get patches and I still sometimes feel totally lost, but in finding this community I found comfort, and friends, and lots of love and laughter and support and that is what prompted me to become involved with this foundation. I attended the Kids Camp last year as a young adult volunteer, and after that, the WA branch manager, Greg asked if I wanted to take on a more official role, as I had just been helping him out unofficially for a few years.

I feel that the foundation has helped me so much, and I would love to extend that love, laughter, kindness and support to everyone in the community.

Happy 10 year anniversary to everyone at the AAAF and to everyone who may be celebrating their Alopeciaversary this year too.

Clara

you can reach Clara at:

**[Clara@aaaf.org.au](mailto:Clara@aaaf.org.au)**



# COMMUNITY STORY

## Sophia



October 2019

Hi, my name is Sophia and I am 12yrs old.

In July, I received my sponsorship for dance. Since then I have been able to do more dancing and especially private lessons, which I have always wanted to do! I am now doing private lessons/a solo dance which I will be performing at my dance school's End of Year Concert.

The song I have been working on recently is 'Lay Me Down' by Sam Smith. I chose this song because it is very emotional and an easy song to work with. Being able to do a solo dance in front of people without hair is something that I have wanted to do for a while and thanks to the AAAF sponsorship program I am able to do that.

I have also been busy doing other troupe eisteddfod's where we have placed quite a few times. By doing these eisteddfods I get to show off my alopecia and inspire others that no matter what you look like it can't stop you from achieving your goals and doing what you love.

Having alopecia has taught me one important thing:

**'Change your thoughts and you can change your world'!**

No matter how I look, I could always want to change and wish that I was "prettier", so why not just love myself for who I am? Otherwise I would've missed so many good memories and good times if I let alopecia take over my life.

This is why I am so grateful for AAAF because they host many events where I get to meet others like me and make lots of friends. I am super excited that in November I will get to see some of the friends I made last year at the AAAF Kids Camp on the Gold Coast! We get to go to Dreamworld which I haven't been to before! Until next time by from Sophia!

**Continued Over**



## COMMUNITY STORY

### Continued

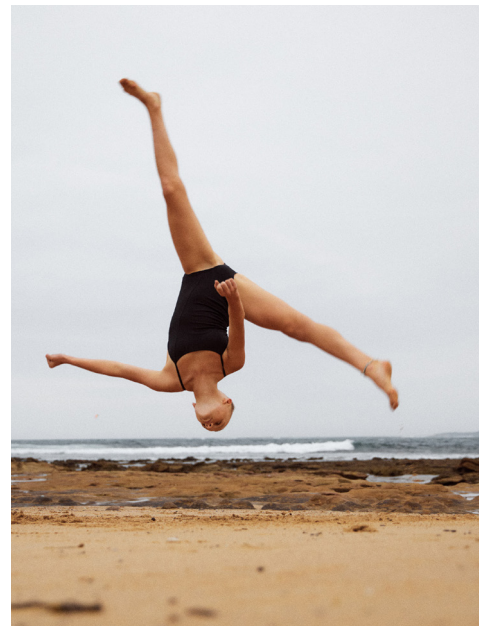
January 2020

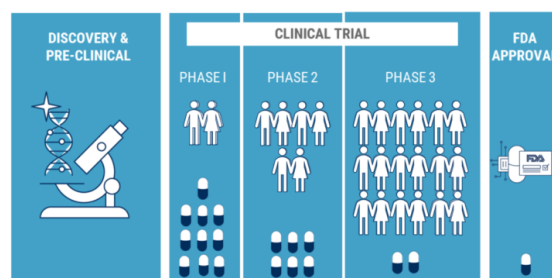
Since my last update I have done many great things. I did my solo at my dance studio's end of year dance concert. Doing that made me feel so good and made me believe that I have really improved as a dancer.

I also did my first ever modelling shoot. This all started because of the ABC news program they did on the Alopecia Areata Adventure Camp 2019. When that was premiering on TV, a professional photographer from New York was watching the program and thought it was really interesting, so she looked onto the AAAP page. She then saw my story and how I have always wanted to do modelling and acting, so she contacted me and the AAAP to say that she would love to do a shoot with me sometime. Modelling is something that I am very passionate about and I will continue to follow my dreams to this day. A big thank you to Sally Griffiths for taking the time to do the photo shoot (The photos turned out amazing).

Thank You to Miss Bri as well for choreographing my dance. This experience has really taught me that anything is possible and that some things take time so I should never give up.

I hope that my story can inspire others to achieve their goals and dreams and know that you can do anything no matter what you look like. I hope that I inspired other kids with alopecia to know that there is always a bright side to life and that true beauty comes from the inside.





A clinical trial into medication for people with Alopecia Areata is seeking participants.

Participants must be 12 years or older, diagnosed with Alopecia Areata and have at least 25% hair loss on your scalp. This trial is available in Sydney, Melbourne, Brisbane and the Gold Coast. This trial is sponsored by Pfizer and builds on previous studies. Participants who took part in other recent Pfizer sponsored trials may be eligible to join this study also.

For more information, please [click here](#).

### **Are you looking to make changes in your lifestyle? Do you seek greater acceptance and improved physical health? Psychological study seeking participants**

Study seeking 48 participants between 18-65, Australia-wide, with any form of Alopecia Areata. This study investigates the impact of acceptance and physical activity (exercise) in mental wellbeing for people with AA. Study participants receive a Fit Bit, which they may keep if they complete the study. This study is for those who seek positive lifestyle changes in their life, which requires a 6 week period of commitment. Options for the study have been adjusted to accommodate current lock down due to COVID-19.

Please note that the Fit bit should be posted back to the researcher if the participants wish to withdraw from the study.

To find out more, please [click here](#).

New treatment option for Alopecia Areata has received breakthrough therapy designation by the American FDA.

This is huge news! There are currently no FDA approved medications for Alopecia Areata in the US, or TGA approved medications here in Australia.

Baricitinib approval as breakthrough therapy is a big step towards getting a treatment option approved here in Australia by our own Therapeutic Goods Administration (TGA).

AAAF are so excited by this step towards having effective, affordable treatment options for Australians with Alopecia Areata supported by the PBS.

[Read more here.](#)



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*'world class designs'*

Rigon Headwear are experts in luxurious and comfortable headwear solutions made from natural products for women and children living with hair loss.

This season you will find a large selection of stunning new prints and amazing products for people with a form of Alopecia Areata in their Christine range.

If you're looking for comfortable, stylish and fashionable turbans and scarves, you can't go past the vibrant and sophisticated Boho Spirit line or the luxurious and timeless Viva range.

For children or ladies with petite head sizes, the Petite Peanut range will most definitely put a smile on your face. If you need cosy and comfy sleep caps to keep you warm at night, or secure and chic swim caps, Rigon Headwear have options for you that are both beautiful and comfortable. The Christine range also features smooth and silky wigliners and soft lift caps that help improve the look and feel when wearing your wigs or other headwear.

Right now Rigon Headwear has a special online offer - Purchase any two turbans or scarves from the Christine line and receive a free gift of the Karuna turban, valued at \$45.

Whether you are looking for soft and comfortable headwear for a sensitive scalp, fun and fashionable scarves and turbans to complete your outfits, or cozy and warm beanies as we head into the cooler months, Rigon Headwear have beautiful styles for you. Rigon Headwear understands the needs of people living with hair loss, and welcome all the friends of Christine to browse their stunning 2020/21 collection. [Click here to view the Rigon Headwear website.](#)



7215 - 37.5 Soft Lift Hat - Light Tan



Style:  
Christine Soft Lift hat - 37.5  
Wool/Polyester with 37.5 Technology

#### CHRISTINE HEADWEAR SOFT LIFT HAT

The Soft Lift Hat from Christine Headwear is a revolutionary new design protected headwear piece, which will provide the perfect fit and lift under your wigs and headwear.

A small hat that will make a big difference to the look and feel of your head coverings, as it gently lifts and adds a fine, natural volume to the back of the head.

The soft, breathable and light 37.5® fabric material will ensure you stay comfortable as it helps the covered area maintain an optimal 37.5-degree temperature - regardless of how you choose to cover it.

To make this clever little lift a light mesh pad has been inserted under a soft top layer. This will add a beautiful rounded shape to the back of your head whilst leaving you comfortable still, feeling nothing but carefully and gently protected.

The results are nothing but fantastic and you'll find your headwear and wigs will get a brand new, fine and elegant finish.



# WHAT'S NEW?

AAAF is happy to announce two new members to our volunteer team, Vivien and Harry.



Vivien is a current medical resident with an interest in Alopecia Areata. In 2018, Vivien conducted a year of clinical research into the systemic treatments for Alopecia Areata. She is passionate about continuing research and helping build awareness and support programs in this field to help patients with Alopecia Areata.

Vivien can be contacted at [vivien@aaaf.org.au](mailto:vivien@aaaf.org.au)



Harry is an empathetic, caring young man who developed Alopecia Areata 14 years ago. He is a strong believer that Alopecia teaches invaluable skills such as resilience and determination, and is here to support anyone who needs advice, guidance or cheering up.

Harry can be contacted at [harry@aaaf.org.au](mailto:harry@aaaf.org.au)



AAAF would like to thank the Genetic Support Network of Victoria for supporting our community through the Margaret Sahhar Grant. AAAF have been supported to create a Volunteer Training and Support Module. This pack will help us to better support our volunteers and aid them in providing the best possible care and service to our community. We are looking forward to rolling it out with our newest volunteer members and working to continually improve our support for our community. AAAF thanks GSNV for supporting our community through the Margaret Sahhar Grant, and all the work they do for communities impacted by genetic, undiagnosed and rare diseases.





This year is AAAF's tenth anniversary. We have a lot planned to celebrate this amazing milestone with you, even if we can't get together in person.

In just a few weeks, we'll be running a very special Christmas-in-July giveaway!

This will be a very special letter-writing competition with some amazing goodies up for grabs. Dust off those pens and keep an eye out for more details close to July.



Are you connected into our social media platforms?

**Here at AAAF we post daily to one of our social media forums.**

Why? Because Social media has exponentially increased the resources for mental health information, support and research shows that people who get support from peers (those struggling with the same problems) have better health outcomes.

## SOCIAL MEDIA LINKS

**AAAF**  
**Linkedin**  
**Facebook**

**Instagram**  
**You Tube**  
**Go Fundraise**

**My Cause**  
**Shopnate**  
**Love Alopecia**



# Did you know

## COVID-19 Update

The Australian Government recommendations for slowing the spread of Covid-19 include social distancing measures. On the basis of this recommendation, AAAF will not be organising any large events until we hear otherwise from health authorities.

AAAF will be planning a range of digital programs over the next few weeks and months to continue to support our community remotely. We encourage all community members to register with us and follow us on Facebook to stay up to date. Our Support Ambassadors, Branch Managers and online Alopecia Support Group services will remain active throughout this period and can be contacted for support or assistance.

AAAF encourage our community to not panic, but maintain strong hygiene practices and follow social distancing guidelines to help slow the spread of this condition. We encourage all questions to be directed to the Health Direct services who are leading communications as this situation develops.

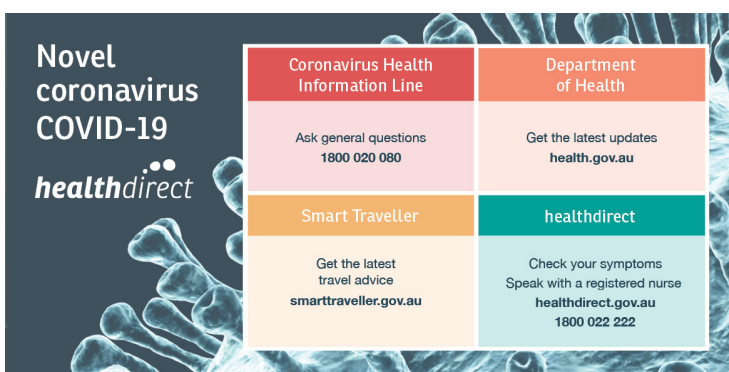
Some common treatment options for Alopecia Areata are immunomodulators, like thiopurines (cyclosporine, methotrexate) and JAK inhibitors. These treatment options can inhibit immune response to viral infections. Hygiene measures (like hand washing and avoiding touching the face) and social distancing measures should be observed, as per the normal guidelines provided by Australian health services. If you require more information about immunomodulators and COVID-19, we recommend contacting the Health Direct services or your prescribing doctor.

To date, all international patients with Alopecia Areata on JAK Inhibitor treatment who contracted COVID-19 had an uneventful course and no hospitalizations.

A global alopecia COVID-19 registry is now live and doctors all over the world are recording patients with alopecia and other hair loss disorders who have developed COVID-19 and where the outcome is known.

AAAF will be acknowledged on this registry.

More information can be [found here](#).



# WHAT'S ON?

## celebrating

AAAF is ten years old in 2020!

As part of our celebrations, we have a competition for you. Can you name ten of our committee members from photos when they were ten years old?

Give it your best shot and you could be one of ten lucky people to win a \$100 gift voucher!

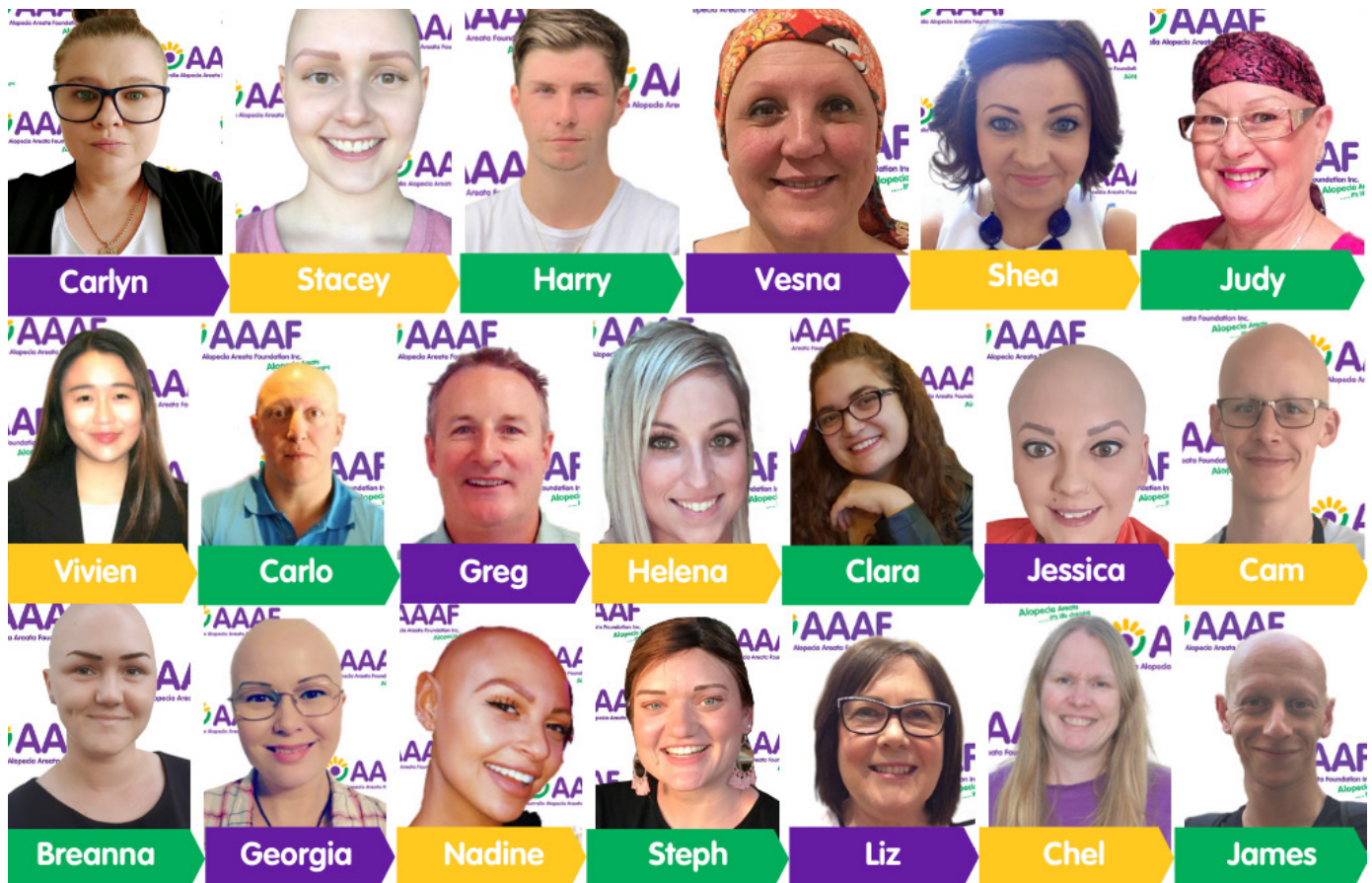
Every entrant will get their name put in the barrel. If you guess all ten committee members correctly, your name goes in twice - doubling your chances!

This competition will be drawn on May 31st 2020.

Entrants must be aged 18 or have permission from a parent/guardian to take part.

To enter the competition, [click here](#).

## years



## Variety Alopecia Areata Adventure Camp 2019

In November 2019, we hosted our third annual camp for kids with Alopecia Areata. Kids from every state in Australia came to the Gold Coast for this amazing weekend. We held one day of thrilling adventures at Dreamworld Theme Park.

Our second day featured self-confidence inspiring sports challenges at BLK Performance Centre. We had an amazing opportunity to share the camp with ABC's 7.30 Report who filmed much of the fun.

Watch the [report here](#).

Unfortunately, the Variety Alopecia Areata Adventure Camp will not be running in 2020 due to COVID-19.

AAAF is passionate about this camp and providing this opportunity to kids and young people living with Alopecia Areata. We hope to see all our wonderful campers in 2021.





## Good Feathers – An Alopecia Story By Max Muller

AAAF is excited to announce a new resource for kids with Alopecia Areata by talented young artist, Max. Max was one of the recipients of AAAF's 2019 Sponsorship Program. He was supported in art lessons. As part of his progress, Max has written, drawn and coloured a fun comic for kids about a young penguin with alopecia.

AAAF are offering to send a specially printed copy of this amazing comic to 25 families dealing with Alopecia Areata, totally free for you.

To request a copy, email: [info@aaaf.org.au](mailto:info@aaaf.org.au)





"Thank you Jeremy you have taught me well Alopecia isn't the end of the world and I can't let it get me down and no I have never thought of becoming a poet aren't you meant to be pushing me on my way to becoming a skier"

WOW

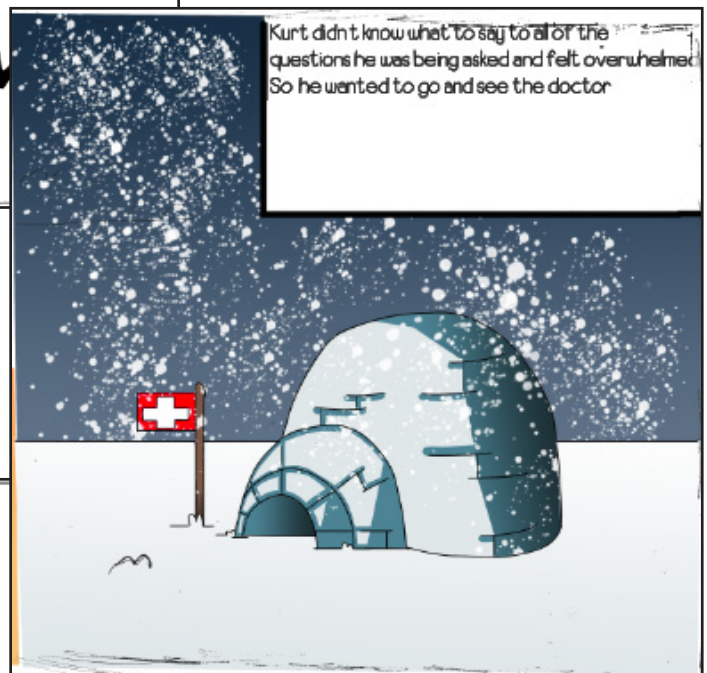
WOW



WOW

Kurt didn't know what to say to all of the questions he was being asked and felt overwhelmed. So he wanted to go and see the doctor

Dr Jevtic explained that Alopecia is caused when one's immune system is too active. This causes a person's immune system to treat hair follicles as a foreign entity like the common cold and so combats it by fighting back causing the hair to fall out. Kurt has no feathers whatsoever. But there are other types of Alopecia where only patches of feathers are lost.



Alopecia Areata

Medical Diplomacy  
or something

