

alopecia uk

Jen Chambers
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*Working with patients for
alopecia research*



alopecia uk

*Working to improve the lives of those affected
by alopecia.*

SUPPORT. AWARENESS. RESEARCH.

- Small national charity established in 2004
- Charity been pulled forwards in the last seven years, significant developments with regards structuring, staffing and resource.
- Improves what we are able to do and how we are able to engage and support.



I'd like to leave you with two key messages

- 1) Involving patients is a good thing! Whether it be research avenues, treatment evaluation or successful outcome definitions.
- 2) Alopecia UK – ways that you can work with us currently and/or in the future.



Some examples of patient input shaping research...

Microbiome

- WCHR – new area of research (becoming popular area of research generally!)
- Case study - fecal transplant
- Caught the attention of leading alopecia researcher
- Already a project underway in the UK on this as a result of founder of AAR-UK listening to patients

New area of research, new treatment potential?

JAKs

- NAAF Registry
- Identified some overlapping areas
- Helped focus where to look



Support at Alopecia UK

Local Support Groups
& national events



Individual – phone, email,
private messaging



Online peer support spaces



It means we are in touch with, and connected to, A LOT of people affected by alopecia. And people talk!

What does this mean with regards to research, treatments and outcomes?

Patients [conversations] can give a potentially interesting insights...

- Around causes... *“Does anyone know what caused [triggered] their alopecia?”*
- Highlights information we already know... *“Just wondering how many people here have a food intolerance, stomach problems or multiple autoimmune disorders?”*
- Potential case studies examples
- Around treatments being tried or potentially being tried.... *“Is anyone else on XYZ?”*
- Feelings towards hair loss and hair growth... *“I want all of it or nothing”*



Overall...

Alopecia 'voice'

- Active
- Increasingly informed
- Engaged – good response rates
- Passionate about improved research, treatment and outcomes
- Want to help

Alopecia UK

- Can help connect
- Bridge the gap between alopecia community and researchers





Research & Alopecia UK

- Supporting researchers to recruit
- Hair Loss Priority Setting Partnership
- Funded some adhoc projects
- In 2018 we facilitated our first round of a new Research Pots Grant Scheme with two 10k pots of funding up for grabs (including a Patient Vote)
- Pulled together a Research Committee and had our first Research Committee Meeting
- Beginning to engage with and support pharma with regards UK Patient Engagement re study design and protocol



Research & Alopecia UK – looking to the future

- Recruiting a Research Manager
- Developing Patient Advocacy Programme
- Increased engagement with researchers and feeding back to the community
- Develop our Grant Schemes & Collaborative Grant Schemes
- Increase data collection

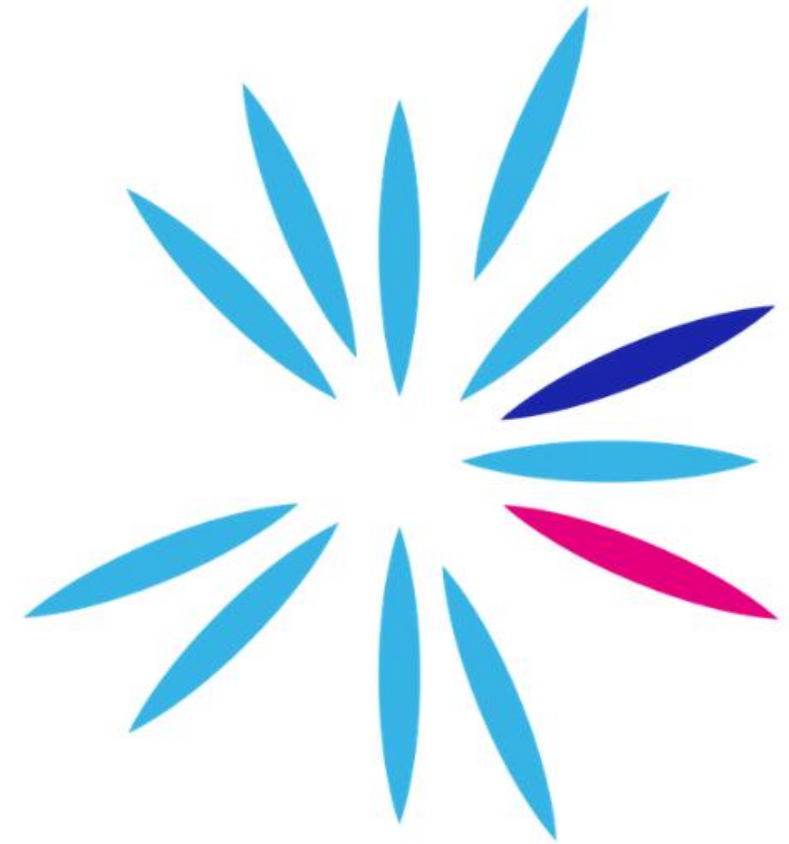
Underpinning it all will be patient involvement. Ensuring that our research workstreams include those with alopecia, both to help establish research avenues as well as inputting in whether they are happy with the potential outcomes and treatments.

Questions?

But also a question for you!

Being a charity that is constantly evolving and developing its workstreams around its aims of support, awareness and research...

What do you need from a UK Alopecia Charity to help you in your work and research?



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www.alopecia.org.uk

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