Are you #AutoimmuneAware?

Four million people in the UK are living with an autoimmune condition - which can cause pain, difficulty, lost opportunities in work and in life, and in many cases place people at risk of early death.

Four million people. That's almost one in every 16 of us.

And autoimmune conditions are on the rise.

Treatments to manage autoimmune conditions are already costing us billions. The rising costs will hurt the public purse further.

But the rise of these connected conditions is underreported.

The four million people affected by autoimmune conditions need your support. We need you to declare that you are #AutoimmuneAware.

And we need Parliament to help autoimmunity gain the recognition it lacks, so that it can stand on its own as a distinct research area – just like cancer, infectious disease and dementia.

Women are 3 times more likely to live with an autoimmune condition than men

400,000 people with type 1 diabetes, 400,000 with rheumatoid arthritis and 100,000 with multiple sclerosis in the UK

What you can do as parliamentarians

With public research funders working to connect immune research, we need you to harness the support of Government.

We want you to:

- Raise awareness: declare you are #AutoimmuneAware in the media and on your own social media channels
- Support Connect Immune Research in Parliament and give autoimmunity the recognition it deserves as a distinct research area with the potential to help four million people
- Write to Government ministers to highlight the need to help link up research across autoimmune conditions

The report was written by Paz García, Senior Research Communications and Engagement Officer at JDRF. References for statistics used in the report are available on request. For more information, visit jdrf.org.uk/connect

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CONNECT IMMUNE RESEARCH

Are you #AutoimmuneAware?

Report for parliamentarians into autoimmune conditions

November 2018

Produced by:

JDRF IMPROVING LIVES. CURING TYPE 1 DIABETES. · VERSUS ARTHRITIS · MS Society · British Society for immunology

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What are autoimmune conditions?

Autoimmunity occurs when the immune system attacks the body. The immune system, which normally protects you from infection, instead targets part of the body and destroys it or stops it functioning properly.

There are over 80 autoimmune conditions, each affecting different parts of the body.

In type 1 diabetes, the immune system destroys the cells that make insulin. In rheumatoid arthritis, the lining of the joints are attacked. In multiple sclerosis (MS), the coating around nerves is damaged.

Autoimmune conditions are poorly understood. In some cases, we know that certain genes or being exposed to certain environmental factors can make some autoimmune conditions more likely.

But that's not the whole story – something is going wrong with the immune system, and we don't know why.

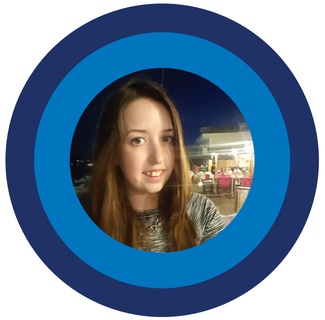
At present, autoimmune conditions cannot be cured.

This means that for most people who develop an autoimmune condition, a lifetime of daily management and potential health complications and pain lies ahead.

Why we must act

The impact of autoimmune conditions

Having one autoimmune condition makes developing another more likely. Up to a third of the four million people affected live with more than one autoimmune condition. This can lead to health needs that are more complex and lives that are more challenging.



Chloe, 25, is a paediatric nurse who works in intensive care and in research. She lives with three autoimmune conditions – type 1 diabetes, vitiligo and an underactive thyroid – which went on to cause secondary Raynaud's.

"My type 1 diabetes is very time-consuming, not only because of the constant management, but also having to explain it to friends and employers for my own safety. There are so many misconceptions around it and, even working in a hospital, I get funny looks when people see me injecting insulin before meals.

The underactive thyroid sometimes feels like the most annoying of my conditions. It only requires taking a tablet once a day, but the dose required changes constantly depending on hormones. If the dose is not correct, I can have issues with controlling my body temperature, fainting and generally feeling tired and grumpy, which is unfair on my family.

I find that Raynaud's though, which was caused by having multiple autoimmune conditions, gets to me personally the most. Raynaud's means my hands and feet go blue and numb, and I struggle with fine motor skills. This means that even simple things like doing up buttons become difficult, which is very frustrating."

And there isn't just a personal cost. The complex and chronic nature of autoimmune conditions mean that there are significant financial costs to treating them.

Direct and indirect costs to the UK for type 1 diabetes, rheumatoid arthritis and multiple sclerosis alone add up to more than £13 billion a year.

Over the last three decades, the incidence of autoimmune conditions has been rising. For different conditions these increases range between 3% and 9% year on year.

We don't fully know why. With numbers and rates for autoimmune conditions increasing, the costs are only set to grow.

Building a future without autoimmunity

CONNECT IMMUNE RESEARCH

It's clear that autoimmune conditions are connected. So rather than study autoimmune conditions in isolation, wouldn't it make more sense to study autoimmunity more broadly, across a range of conditions?

We believe that by working together, research into autoimmunity can progress faster.

By working with scientists with expertise in different conditions, we could discover that one treatment in a single autoimmune condition is a skeleton key, unlocking impact far beyond the initial indication.

This could dramatically reduce costs and speed up development of treatments for millions of people with different autoimmune conditions.

That's why we're launching Connect Immune Research: to bring together researchers from different fields to study the mechanisms of autoimmunity in a non-condition-specific way.

Professor Yanick Crow, from the University of Edinburgh, has been awarded the first ever Connect Immune Research grant to make this concept a reality.

He will work with research specialists from different conditions to understand the role of immune system protein interferon in autoimmunity. The sooner we can understand autoimmunity, the sooner we will find a cure for the estimated four million people who live with autoimmune conditions in the UK.

Professor Yanick Crow

Wellcome and the Medical Research Council (MRC) supported the development of Connect Immune Research. The MRC has since set up its own initiative to help bring together immune researchers working on different conditions.

Together, we have established a body of public funders ready to collaborate with patients to foster further progress.

WILL YOU JOIN US?

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