

# How to make life better for people with coeliac disease

**Dr Bob Anderson\* challenges people with coeliac disease to play a central role in guiding research and medical awareness.**

While browsing a “coeliac” chat room I found a comment from a blogger indicating that they wouldn’t be interested in having a treatment that might replace their need for a gluten free diet. Being on a gluten free diet was such a large part of this blogger’s life that they felt he/she wouldn’t know what to do if it was no longer needed.

Initially, I wondered why I had invested the last ten years of my life in research developing a drug that might replace the need for gluten free food for people with coeliac disease. But then I reflected that outside those people directly affected by coeliac disease, very few appreciated quite how substantial the impact of a gluten free diet can be. Equally, is a cure for coeliac disease what people with coeliac disease want, and what would people affected by coeliac disease do to find a cure?

Returning to the Internet, I began browsing websites for patient support groups – for Type-1 diabetes, for multiple sclerosis and then for coeliac disease. Type-1 diabetes and multiple sclerosis give prominence to “Research”, “Find a cure”, “Support research”, and “Make a donation here”. I found news of much research activity promising cures for both these diseases. Researchers in the UK recently received US\$1million from a USA-based support group to accelerate development of a therapeutic vaccine for multiple sclerosis. Meanwhile, the Juvenile Diabetes Research Fund (JDRF) has raised and invested hundreds of millions of dollars to fund research to find a cure for Type-1 diabetes. Indeed,

over the last five years, the USA alone has contributed almost 2,500 medical research papers to the world medical literature on Type-1 diabetes, clinical trials of possible therapies are also underway and much of this activity is directly supported by the JDRF.

Coeliac disease affects about 1% of the population in most Western countries including the USA; it is about twice as common as Type-1 diabetes, and seven-times more common than multiple sclerosis. Coeliac disease, Type-1 diabetes and multiple sclerosis are each intimately related to certain genes that govern “immune recognition”. In coeliac disease and Type-1 diabetes, the genes for HLA DQ2 and DQ8 dominate; in multiple sclerosis genes for HLA DR2 are important. In each of these diseases the body’s immune system mistakenly turns upon itself or in the case of coeliac disease, mounts a destructive immune response against an innocuous food protein, gluten.

Substantially more is known about the immune reaction that causes coeliac disease than either multiple sclerosis or Type-1 diabetes. Now, coeliac disease is even being described as the “model autoimmune condition”. For people with coeliac disease, this knowledge offers the possibility of developing treatments to improve or possibly replace dietary therapy. And for clinical trials to test new treatments, coeliac disease has the advantage that the affected organ (the small intestine) is relatively accessible, the immune reaction to gluten is well characterised and can be “safely” reactivated for a short time by reintroducing dietary gluten. On the face of it, coeliac disease seems better placed for the discovery of a “cure” than either multiple sclerosis or Type-1 diabetes.

When I turned my attention to the coeliac disease websites, I found a lot of information about the only current treatment for coeliac disease, gluten free diet, but very little about a future vision or cure. Although many sites report on research being undertaken, organised support for research in the manner described on the multiple



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sclerosis and Type-1 diabetes sites is found on very few coeliac disease websites. The only reports of funding for research by coeliac support groups were at the Celiac Sprue Association (USA) which offered US\$5000 for small projects, and Coeliac UK which last offered research grants and fellowships (of which I was a beneficiary) in 2005.

In short, the research agenda in coeliac disease has not been lead by coeliac disease support groups. It can be surmised that since research funding from patient support groups is very limited, nearly all the research funding for coeliac disease is from government-funded organisations, such as the National Health and Medical Research Council in Australia. What effect does this have, and does it matter?

We think over 2.5 million Americans have coeliac disease, and that perhaps three-times as many people are affected today as fifty years ago; coeliac disease is a common medical problem in the USA. Over the last five years the USA contributed nine medical research papers per year on coeliac disease compared to almost 500 on Type-1 diabetes. Australia contributes about 60 medical research papers on Type-1 diabetes per year, and on coeliac disease seven. Finland with a population about 1/60th that

of the USA and 1/4 that of Australia contributes more research papers on coeliac disease than the USA (eleven per year). In Finland, about 50% of the people affected by coeliac disease have been diagnosed. In the USA, about 5% of the people affected by coeliac disease have been diagnosed, and in Australia about 25% have been diagnosed.

My interpretation of these figures is that research publication reflects a general level of awareness of coeliac disease. In my experience as a medical student and then as a junior doctor studying for (many) exams, doctors' awareness of a condition is lead by "high level" medical experts who usually also undertake research in the disease they are passionate about. In universities, the number and quality of research publications is the most important determinant for promotion and eventually becoming a "professor". In other words, research funding attracts and ensures engagement of medical experts in particular diseases. In general, medical research is undertaken because funding for it exists, not necessarily because the medical problem in question is exceptional. Competition for scarce research funding is ferocious. In Australia and many other countries, scientists judge one another's research proposals to decide which deserve funding. Although medical need is an important factor, the track record of a researcher and where the researcher last published their research is often a deciding factor in whether a research project is funded.

Patient support groups can drive an agenda set by the people with their disease and offer funding to stimulate research and awareness in

their disease. Why not attract the best research minds to coeliac disease by offering research support and ensure that scientists focus on long-term goals such as a cure rather than be preoccupied with the research journal where they last published a paper? This has been the highly successful strategy adopted by the JDRCF.

Australia is in the unique position of having expert medical specialists and researchers based at the country's leading hospitals and research centres taking an interest in coeliac disease. Awareness of coeliac disease is also relatively high in Australia probably because these experts in medicine, science and dietetics have become involved in coeliac disease and initiated successful research programmes.

Coeliac disease has been a neglected medical condition; ignorance and deficiency of good quality research has fuelled (medically) unjustified use of gluten free food while the majority of people with coeliac disease remain undiagnosed. Australia is leading the way in recognising alternative causes such as fructose intolerance to explain why some people might have improved irritable bowel symptoms when foods including gluten are avoided.

This new coalition of patients, health professionals and researchers needs to be coordinated and funded if coeliac disease is to be effectively managed in Australia and elsewhere. Organisations like the JDRCF provide wonderful models that realign the agenda for important diseases by embracing researchers and clinicians but which are guided and funded by people affected by the disease.

The Coeliac Research Fund (CRF) has been established in Australia

to promote, "Awareness, Diagnosis, and Research" and "Pursue a Vision to Cure, Control and Prevent Coeliac Disease". The coeliac communities in Australia and New Zealand are perhaps an exception to the overseas experience. The CRF has been funded with the administrative and financial support of the coeliac societies in Australia and New Zealand. In addition individual members of coeliac societies have contributed to the CRF (previously ANZCRF) which has enabled the funding of some initial research grants.

My prediction is that if the CRF is supported and flourishes, Australians will have better medical care, benefit more quickly from research breakthroughs made overseas, will be able to lobby for better care, and may even contribute to a cure for coeliac disease. It is time people with coeliac disease played a central role in guiding research and medical awareness. Coeliac disease affects a lot of people and costs Australia a lot of money, more research and better informed health carers could improve many lives and save much of the money spent unnecessarily on the gluten free diet by people who do not have coeliac disease. The Coeliac Research Fund provides Australia with an ideal opportunity to achieve these goals. I encourage you to support the Coeliac Research Fund in its first fundraising appeal as an independent organisation.

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