

Our open letter to doctors and endocrinologists involved in diagnosing and treating hypothyroidism, to the organisations that fund the diagnosis and treatment of hypothyroidism, to the organisations producing guidelines regarding the diagnosis and treatment of hypothyroidism and to the organisations that enforce the guidelines

1st November 2018

To whom it may concern,

We feel compelled to share our story with you for reasons that will become apparent as you read on. We are identical twins. When we were born, nobody could tell us apart and so it continued. Here's a photograph of us at around five years of age looking identical.



However, around the time of our sixth birthday, one of us [Donna] started to develop various symptoms including shortness of breath, severe lack of energy and excessive weight gain, even though we were eating the same, and she started having great difficulty with her schoolwork. Our parents were concerned and during that period, Donna was taken to see doctors on numerous occasions but nobody was able to diagnose her correctly and more time was lost.

In the meantime, the other one of us [Coralie] became taller than her identical twin. Donna declined further and was demoted to a different class from Coralie at school. We no longer looked like identical twins as can be seen in the next photograph.



Eventually, Donna was seen by a brilliant National Health Service (NHS) paediatrician who knew at a glance what was wrong and carried out tests to confirm his diagnosis of thyroid failure or hypothyroidism. It was necessary for Donna to be prescribed thyroxine tablets that she had to take daily.

Thanks to ongoing prescriptions of thyroxine, Donna's growth and development caught up with Coralie's, Donna lost her excess weight, regained her energy and her schoolwork improved. We eventually looked alike again, as can be seen in the next photograph, and we were put into the same class for the final year of junior school.



Unfortunately, during that school year, Coralie developed various symptoms including shortness of breath, lack of energy and weight gain. She was referred to the same paediatrician who was treating her twin and subsequently diagnosed with hypothyroidism too and was also prescribed thyroxine on an ongoing basis. As a result of treatment, Coralie lost the excess weight, gained energy and was no longer breathless on exertion. We regained parallel growth and development and looked alike again.

In adulthood, we were both working and getting on with our lives. However, due to blood test results, NHS doctors had concerns that our thyroxine dose (that we had been prescribed since childhood for our hypothyroidism and had never given rise to any symptoms of over-activity) was too high and had to be reduced. Following various alterations to our dose in accordance with our thyroid stimulating hormone (TSH) levels rather than our symptoms, we were put on a thyroxine dose that was $\frac{3}{4}$ of the dose that we had been taking since childhood.

On $\frac{3}{4}$ of our original dose, we suffered from numerous symptoms including dry, thickened scalp, breathlessness, cold sensitivity, carpal tunnel syndrome, abnormal endless exhaustion, reduced appetite, headaches, chest pains, back pain, puffiness, tinnitus, nausea, retching, balance problems and loss of our functionality. We had weight gain despite a reduced appetite. Because we are identical twins, it was clear to us that our parallel problems in adulthood were due to under-treated hypothyroidism. Despite this, our low TSH levels meant that our doctors were unwilling to increase our thyroxine dose. Much time passed before we succeeded in finding an excellent doctor who recognized that we were suffering from under-treated hypothyroidism. This private doctor from Scotland, to whom we remain thankful, carried out thorough clinical assessments, studied our test results, took a detailed medical history and confirmed that our symptoms were caused by under-treated hypothyroidism.

In accordance with our clinical needs, he prescribed an increase in our thyroxine and over time, he changed our treatment to thyroxine and tri-iodothyronine, then to tri-iodothyronine, then to natural desiccated thyroid (NDT) treatment, which contains tri-iodothyronine. Changes to our treatment were made gradually under medical supervision and we were carefully monitored to ensure that we were neither under-treated nor over-treated with thyroid hormone treatment to avoid any adverse consequences. Tri-iodothyronine and tri-iodothyronine containing treatment were essential to our recovery in adulthood. Despite its efficacy during our childhood, thyroxine is no longer adequate for our needs nor tolerable. **Therefore, ongoing natural desiccated thyroid treatment, which contains tri-iodothyronine is essential for us to remain alive and well.** Hence, we are grateful to the NHS doctors and NHS endocrinologists in Wales who have enabled us to obtain ongoing prescriptions for our natural desiccated thyroid treatment. Our prescriptions are funded by the NHS. Our treatment is imported from the United States of America. Next is a photograph of us taken since our recovery from under-treated hypothyroidism in adulthood.



In addition, it has been recognised that in our case, there is not a consistent correlation between our thyroid function blood test results and our symptoms of hypothyroidism.

We are the authors of the book *Hypothyroidism in Childhood and Adulthood* (which was published by Nottingham University Press) and several other books on the topic of hypothyroidism or twins/multiples. We are currently writing another book. We have also given presentations about hypothyroidism at conferences in the UK and abroad and we have been interviewed for newspapers, magazines and the radio.

However, we are concerned that some patients with symptoms of hypothyroidism are not being diagnosed and remain ill. Some are being diagnosed with hypothyroidism but are not being treated in accordance with their individual needs and remain ill due to under-treated hypothyroidism. Some are being treated in accordance with their needs and have recovered from hypothyroidism but are having their thyroid treatment withdrawn due to the inappropriate enforcement of guidelines that do not take into account the existence of such patients and they have become ill again due to a return of their symptoms of hypothyroidism. Some are being treated in accordance with their needs and have recovered but are having their thyroid treatment withdrawn due to withdrawal of funding and have become ill again due to a return of their symptoms of hypothyroidism.

Doctors should not be deterred from carrying out any of the life-saving work that they do and therefore, they should be free to prescribe life-saving liothyronine [tri-iodothyronine] and life-saving treatments containing tri-iodothyronine such as natural desiccated thyroid treatment to individuals with hypothyroidism when needed.

We are grateful to all individuals and groups who are raising awareness of hypothyroidism and who are campaigning for improvements to the current situation. As a result of their efforts, we hope that all patients with hypothyroidism, whether children or adults, will be diagnosed promptly by their medical doctor and prescribed the optimal dose and type of thyroid hormone treatment for their individual needs be that tri-iodothyronine, thyroxine, natural desiccated thyroid treatment or some combination of these treatments so that they can recover and get on with their lives.

Yours faithfully,

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