



22 May 2006

The Addison's rose: the gift of life

How the price of four roses a year (£48) can keep someone with Addison's disease alive and well

Peter Beales Roses are launching a new rose, Our Beth, with 10% of sales proceeds to be donated to the Addison's Disease Self-Help Group. The Addison's rose is dedicated to Beth Loasby, a much-loved member of the Peter Beales staff who lived successfully for many years with her Addison's disease and insulin-dependent diabetes. She died unexpectedly from complications resulting from her diabetes.

The Addison's Disease Self-Help Group is grateful to the Loasby family and to Peter Beales Roses for their generous support of its work through the launch of this lovely new rose. Our Beth is a delightful garden rose with large, fragrant blush-pink flowers and glossy, deep-green foliage.



"We are just thrilled to receive this bequest from Peter Beales Roses and the Loasby family", said Deana Kenward, President of the Addison's Disease Self-Help Group. "This rose is a very touching reminder that life is a precious gift."

"We hope this rose will give pleasure to many people in their gardens, with the added satisfaction of knowing that they are helping to sustain a small community of people with a rare, potentially fatal endocrine condition"

The ADSHG: working to support people with adrenal failure

The Addison's Disease Self-Help Group works to support people with adrenal failure and to promote better medical understanding of this rare condition.

"Sharing information and practical experiences among our members about daily management of self-medication, including when and how much to increase for illness, is the core of our activity.

"Better awareness can help to save lives and may prevent unnecessary deaths and disability."

We also work in co-operation with some of the UK's leading adrenal specialists to promote broader medical understanding and effective management of this rare condition. For example, we have worked together to develop simple guidelines for the treatment of adrenal emergencies (see picture).

We make all of our patient education materials freely available on our website at www.addisons.org.uk. This information can help people and their families to obtain the treatment they needed in an emergency, preventing adrenal crisis. Newly-diagnosed individuals and their families often find our website a valuable source of information and reassurance.



For information about the work of the Addison's Disease Self-Help Group, or to join the group or make a donation, please visit our website at www.addisons.org.uk

Addison's disease: the deadly loss of adrenal hormones

When Dr Thomas Addison first identified adrenal failure among his poor, tuberculosis-ridden patients in inner London in 1849, there were no medicines to keep such patients alive. Death inevitably followed within a short time. This is because two of the hormones produced by the adrenal glands – cortisol and aldosterone – are essential for life.

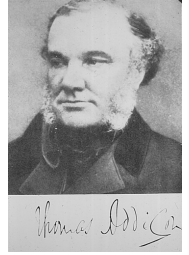
The Addison's Disease Self-Help Group works to support people with adrenal failure and promote better medical understanding of this rare condition. Registered charity 1106791.

<http://www.addisons.org.uk>



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The condition of adrenal failure is named after the good Dr Addison. Whereas in Victorian London it was largely caused by a reaction to tuberculosis infection, in modern-day Britain it is mostly 'autoimmune' – of unknown origin.



It is fashionable to describe cortisol as the "stress hormone" and there are many popular journalistic articles to inform you that too much cortisol is bad for you. But only rarely will you find it explained that too little cortisol is just as damaging, leading to extreme muscle weakness, difficulty standing up, nausea, vomiting and, eventually, to a loss of consciousness and an early death. Typically, this severe but non-specific illness is accompanied by a deepening skin colour, so that a very sick individual can look deceptively healthy – fashionably thin and tanned.

The 20th century development of life-giving medication

It was not until the 1930s that scientists in the United States synthesized a chemical form of the vital adrenal hormone - cortisol - that could keep patients with Addison's disease alive. President John F Kennedy was one of the first to receive the new miracle drug, cortisone. It was not until the early 1950s that cortisone became available in commercial quantities in the UK.



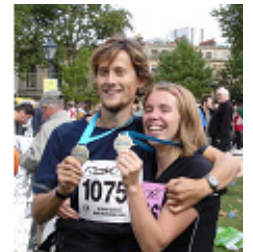
Some of the first 'generation' of post-war Addison's patients are still with us today, now in their 60s or 70s. Pat Beeching, a member of the Addison's Disease Self-Help Group, recalls that her early Addison's medication was so expensive it required the personal authorisation of the Minister of Health for her to receive it.

The price of four roses a year can keep someone with Addison's alive and well

Today, a year's supply of Pat Beeching's essential, life-giving adrenal medication costs the NHS less than £48.00. The price of around four roses a year supplies the medication needed to keep someone with Addison's alive and well.

It is possible to lead a 'normal' life with Addison's

With the right balance of daily medication, people with Addison's disease can lead full and active lives. Steve Dale has completed both the **Bristol and Bath half-marathons** within the past year. Nick Willson has recently been trekking in the **Himalayas**.



The deadly risks of adrenal crisis

Yet living with Addison's disease is not all plain sailing. The daily medication needs to be taken two or three times each day, at the right time of day. A delay of two hours in taking the next dose will see many people with Addison's disease become weak or dizzy, possibly nauseous and forgetful. In the event of serious illness or injury, extra medication is needed rapidly, and an emergency injection of 100mg hydrocortisone may be required. Without this extra medication, the patient may experience adrenal crisis. This is a life-threatening condition with a rapid drop in blood pressure, potentially leading to cardiac arrest or stroke.

Addison's disease: how rare is it?

The most recent research puts the rate of diagnosed, treated Addison's disease among European populations at 140 per million, or around 8,400 cases in the UK. This makes it roughly two hundred more rare than diabetes, another endocrine condition which sometimes develops along with Addison's, as it did in the case of the late, fondly-remembered Beth Loasby.



For all media enquiries please email: media@addisons.org.uk