The Canadian Addison Society

La Société canadienne d'Addison

ISSUE NO.1 (abridged) **Addison Info** **March 1995**

A word of welcome

Living with a rare disorders Is never easy, especially with Addison's since doctors don' t know much more about It than they did In the 1960's. People still die from it. Recently a little girl died because doctors could not figure out what was wrong with her. I am sure many of us have horror stories like that. We would like you to share them with us. We are putting out this newsletter as a way of staying in touch with each other and sharing Information. We hope you will get in touch with us.

The association also holds meetings so that Addisonian's can meet each other and share their experience and feeling about the disease. We hope that you will find the newsletter useful and we are waiting for your comments.

Isabelle Clift

The Birth of the Association

This is the first edition of the Canadian Addison Association Newsletter. This is your newsletter and we welcome your Input and your questions.

On September 24 1994, eight Addisonian's got together to share their story and answer each other's questions. We also founded the Association and decided to form a group to support present and future members.

Greeta Fraser

Did you know?

Salt: there is no evidence that any particular diet or nutrient by itself causes Addison's disease. If a person has Addisons and has not been diagnosed, diets that are low in salt can make Addisonian's feel worse. Because people with Addison need extra salt, without It they will feel weaker and experience more fatigue. Once diagnosed, they should maintain normal salt intake. However, in times of stress, they should take extra salt as well as extra cortisone.

From the N.A.D.F.

Cortisone and Osteoporosis

Cortisone in high doses can increase the risk of Osteoporosis, which can lead to fractures of the spine or the hip. As most Addisonians take small replacement doses, this does not apply. But if you've been on the medication for a long time, it would be a good Idea to discuss this problem with your doctor.

People with Addison's are somewhat more susceptible to have a disease called myasthenia gravis. So if you have been experiencing muscle aches and pain you should consult your doctor.

Shirley's Story

Lloyd and I were married in 1951. In 1954, I was twenty-eight and our daughter was born. Within the next seven years, I believe the illness took over.

When my daughter Donna was nine years old, I was thirty-five, and we went by train to Alberta. All the way there I was ill, plus being dizzy had to lie down and was sick to my stomach, but did not know what was happening

That went on all fall and winter until April 1st I961, weighing seventy-two pounds. I was in Lindsay hospital until the end of the month. Dr. Arnup finally told my family his conclusion was that I had Addison's disease.

When I left the hospital, I weighed ninety-eight pounds and had received ninety-eight cards!. I was to take cortisone so we went lo the drug store. Within two lo three weeks, I was back in hospital with an Addison's collapse.

I was in and on I. of hospital for the next two and a quarter years and it was getting us all down. Lloyd was on shift work. He was the one who carried me to and from the bathroom. Mom and Dad were trying lo run a service station and lunch counter next door and we were trying to bring up a daughter who didn't know how ill her mom was.

By accident, we found out the cortisone I was taking was synthetic and was causing the collapses, low blood pressure, and sick stomach. We went to another drug store and had a long talk with the two druggists. They got in touch with the Upjohn Drug Co. in the States and I have been taking their hydrocortisone ever since.

During this lime, I never had any more children so we decided to put our name in to adopt a baby boy. I had more collapses, and never thought I'd be well enough to be accepted, but when Donna was ten, our son came. He was just five days old and we were so happy.

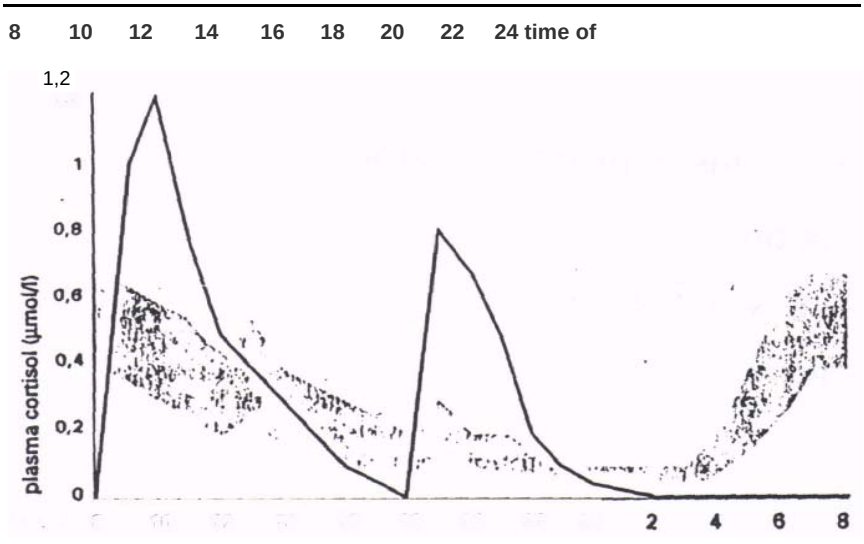
Then, two weeks before his first birthday, I became ill again. Our doctors were both on holidays. Dr.Koyner Snr came to our house, got an ambulance, and I was rushed to

Peterborough hospital. I told the specialist I had to be home for my son's first birthday and made it the day before. Through a girlfriend in Cameron whose sister has Addison's, I was referred to Dr. R HI Sheppard at Western Hospital. I went there for three weeks under his care and stayed with him when he went lo Sunnybrooke. I sometimes went twice a year and then down lo a yearly checkup. In June, after twenty-six years, he retired. It was like losing one of the family for me to say good-bye. As of now, I go lo my GP in Lindsay and am fine. He has many letters from Dr. Sheppard regarding my disease.

Shirley Shier , Cameron Out.

The principle of treating a disorder such as Addison's Disease - which is characterized by inadequate production of one or me re hormones - is simple: the hormone shortfall is supplemented with tablets and the problem should be solved. The patient is not cured, but thanks to this replacement therapy he or she ought to be able to lead a reasonably normal life. If only it were so simple. We sometimes tend to forget that the treatment we call hormone replacement therapy cannot hold a candle to the balanced regulatory mechanisms which enable our endocrine organs to fine-tune their activities to the needs as indicated by their hormones. Figure 22 schematically shows the difference in the plasma cortisol levels between a healthy person and a patient with Addison's Disease who is receiving a replacement dose of hydrocortisone twice a day. As you can see, the plasma cortisol level of the Addison patient is either too high or too low for most of the day.

figure 22
Plasma cortisol levels of a patient being treated with hydrocortisone (20 mg at 08.00 hours and 10 mg at 18.00 hours) compared with the average levels of healthy persons



day (in hours) Addison patient — Healthy Persons
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Modified from d«U published by Kley and KrO.k.mpor 1878 and Khilid et •l. 1982