

1

00:00:00,182 --> 00:00:16,986

This series presents information based in part on theory and conjecture.

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00:00:16,986 --> 00:00:21,527

The producer's purpose is to suggest some possible explanations, but not necessarily

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00:00:21,527 --> 00:00:25,188

the only ones to the mysteries we will examine.

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00:00:25,188 --> 00:00:30,029

Ladies and gentlemen, may I come in?

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00:00:30,029 --> 00:00:33,030

May I crave your attention for a few moments?

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00:00:33,030 --> 00:00:40,471

Moments well spent, my friends, to show you something, a phenomenon, the like of which

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00:00:40,471 --> 00:00:44,872

you may travel the old world over and never see again.

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00:00:44,872 --> 00:00:52,674

In London, in the 1880s, a strange misshapen figure appeared in a small carnival side show.

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00:00:52,674 --> 00:00:58,676

He, elephant man, a grotesque freak of human nature.

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00:00:58,676 --> 00:01:03,677

And yet, he started out in life just like you and me.

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00:01:03,677 --> 00:01:10,678

But one day, while visiting a travelling service, his poor mother, a five-geliac creature, six

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00:01:10,678 --> 00:01:15,679

months with child, was terrified by a patty dog.

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00:01:15,679 --> 00:01:23,681

Hey, elephant, you sir, the consequence of this overwhelming misfortune, I'm about to

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00:01:23,681 --> 00:01:25,682

show you now.

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00:01:25,682 --> 00:01:29,683

Don't let this wonderful educational opportunity pass you by.

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00:01:29,683 --> 00:01:33,684

Would you kindly step away, ladies and gentlemen?

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00:01:35,684 --> 00:01:41,686

Who was the elephant man and what caused his grotesque appearance?

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00:01:46,687 --> 00:01:53,688

In the London of the 1880s, horse-drawn carriages of the rich were never to be seen in areas

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00:01:53,688 --> 00:01:59,690

like Whitechapel Road, which was, as Dickens might have described it, filthy, festering,

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00:01:59,690 --> 00:02:02,690

and overhung with the smell of decay.

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00:02:02,690 --> 00:02:08,692

Tottering rows of blighted housing, an abundance of unwashed children, where the only escape

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00:02:08,692 --> 00:02:12,693

was to be found in a bottle.

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00:02:12,693 --> 00:02:17,694

Although the finest hospital in London was in this area, there were still large gaps in

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00:02:17,694 --> 00:02:20,695

medical knowledge.

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00:02:20,695 --> 00:02:26,696

Poverty-bred diseases rarely surprised the doctors of London Hospital.

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00:02:26,696 --> 00:02:32,697

John Merrick's case came to the attention of Dr. Frederick Treves, later the physician

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00:02:32,697 --> 00:02:36,698

of Edward VII.

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00:02:36,698 --> 00:02:41,699

His account of the Merrick case is a classic in medical literature.

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00:02:41,699 --> 00:02:45,700

The words are taken from his actual notes.

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00:02:45,700 --> 00:02:56,703

I first saw John Merrick or the Elephant Man, as it became known, in November of 1884.

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00:02:56,703 --> 00:03:03,705

One of my junior house surgeons had seen an exhibition of freaks in a disused warehouse

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00:03:03,705 --> 00:03:08,706

off the Whitechapel Road, right near the London Hospital where I worked.

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00:03:08,706 --> 00:03:14,707

The afternoon I went, I found the exhibition temporarily closed.

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00:03:14,707 --> 00:03:20,708

I asked who the proprietor was and where I might find him.

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00:03:20,708 --> 00:03:23,709

I sought him out and we struck a bargain.

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00:03:23,709 --> 00:03:29,711

He would give me a private showing for the payment of one shilling.

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00:03:29,711 --> 00:03:33,711

We went into the warehouse, which was very cold, very dank.

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00:03:33,711 --> 00:03:38,713

We went through numerous passages up many stairs.

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00:03:54,716 --> 00:04:02,718

Finally came to the room where John Merrick was sitting hunched in a corner.

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00:04:03,718 --> 00:04:05,719

Here are you, Governor.

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00:04:05,719 --> 00:04:09,720

First, I couldn't quite see him.

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00:04:09,720 --> 00:04:12,721

He was just a hunched figure in the distance.

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00:04:12,721 --> 00:04:24,723

And as we got closer, he turned to me and revealed himself to be one of the most disgusting specimens

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00:04:24,723 --> 00:04:29,724

of humanity that's ever been my misfortune to lay eyes upon.

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00:04:29,724 --> 00:04:36,726

The proprietor said to him rather harshly as if speaking to a dog.

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00:04:36,726 --> 00:04:38,727

Stand up!

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00:04:38,727 --> 00:04:42,727

As poor man stood up.

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00:04:44,728 --> 00:04:53,730

You know, in my profession, as a doctor, I have seen many gross deformities and mutilations.

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00:04:53,730 --> 00:05:07,733

But I can honestly say, never before or since have I seen a more pathetic, disgusting spectacle from Port John Merrick.

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00:05:07,733 --> 00:05:17,736

This is the skeleton.

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00:05:17,736 --> 00:05:24,737

The curator of the London Medical Museum, Percy Nunn, discusses the actual skeleton of John Merrick.

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00:05:24,737 --> 00:05:34,740

The fact that he had this terrifically grotesque appearance caused by the multiple growths of both bony tissue and also of the skin.

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00:05:34,740 --> 00:05:46,742

Although he seems to be short in stature, this was attributed to the fact that he did have a scoliosis or curvature of the spine which reduced his height by at least six inches.

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00:05:46,742 --> 00:05:55,744

And also, the pelvic basin is twisted in such a manner that he became quite a cripple.

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00:05:55,744 --> 00:06:03,746

He has this throats of bone on the head and down the right-hand side of the skeleton.

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00:06:03,746 --> 00:06:14,749

The cast itself was taken when Merrick died and the cast is a true replica of the way he looked during the time that he was alive.

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00:06:14,749 --> 00:06:27,752

The jaw of the elephant man is inclined to the right and it was here that the first formation of bony growths manifested itself about the age of four and a half years.

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00:06:27,752 --> 00:06:37,754

During the time he reached the age of eleven, the whole of the head, including the forehead, began to show signs of these bony growths.

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00:06:37,754 --> 00:06:44,756

This is the cast taken at death of the elephant man's left hand, as you see there.

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00:06:44,756 --> 00:06:56,759

And you will notice that this is almost a normal hand as against the right hand which is here and this is where the disease really took place.

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00:06:57,759 --> 00:07:14,763

The right foot which I have here was also greatly defaulted.

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00:07:14,763 --> 00:07:19,764

Dr. Trees recalls the disquieting effect John Merrick had on him.

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00:07:19,764 --> 00:07:26,765

I couldn't get the experience out of my mind and I went back and I confronted the showman.

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00:07:26,765 --> 00:07:35,768

You don't seem to realise if it hadn't been for me giving him employment, where would he be? He'd

be in the workhouse shoveling stones.

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00:07:35,768 --> 00:07:44,770

When I took him in he had nothing. I took him in out of the kindness of my art. I'm a kind-hearted man myself. I've been like a father to him.

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00:07:44,770 --> 00:07:54,772

No, no, I became very angry. I was disgusted with the way that poor John Merrick was living. He was living in an absolute filth and squalor and he was being exploited by this man.

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00:07:54,772 --> 00:07:58,773

And I had come to do something about it. So we took him away.

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00:08:09,775 --> 00:08:19,778

I decided after a while that the best course would be for me to provide John Merrick with a home of sorts and some sort of security.

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00:08:19,778 --> 00:08:28,780

It wasn't altogether a altruistic decision. I, as an anatomist, wanted to study him from a medical point of view.

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00:08:28,780 --> 00:08:33,781

Dr. Trees admitted this man himself.

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00:08:33,781 --> 00:08:35,781

The head nurse remembers.

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00:08:35,781 --> 00:08:42,783

Which I found rather audacious of him, although I suppose he had his own reasons.

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00:08:43,783 --> 00:08:47,784

Initially I felt rather annoyed. Or very annoyed, in fact.

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00:08:47,784 --> 00:08:51,785

Because in fact it was irregular, most irregular.

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00:08:51,785 --> 00:08:55,786

We have very strict rules here, made for very good reasons.

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00:08:55,786 --> 00:09:03,788

One of our main rules is that we do not admit incurable. We just simply cannot afford the beds.

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00:09:03,788 --> 00:09:08,789

Nor our nurse's precious time. We have many casualties here. We have industrial accidents.

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00:09:08,789 --> 00:09:11,790

We have to have a certain number of beds always vacant.

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00:09:11,790 --> 00:09:17,791

We provided him with a room in the Blondon Hospital.

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00:09:17,791 --> 00:09:23,793

And he lived there, I think, in relative peace until he died.

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00:09:26,793 --> 00:09:32,795

When I saw the face for the first time, that's something I would rather forget and I put it to the back of my mind.

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00:09:32,795 --> 00:09:40,797

The first I was almost physically sick and as a trained and experienced nurse, one is not proud of that.

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00:09:40,797 --> 00:09:44,797

One has seen accidents. One has seen terrible sites.

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00:09:44,797 --> 00:09:50,799

But this was something quite indescribable.

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00:09:50,799 --> 00:09:55,800

One could not help being deeply affected by this case, this particular case.

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00:09:55,800 --> 00:09:59,801

Because here was a man we could have turned away.

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00:09:59,801 --> 00:10:04,802

And here was someone that indeed we could help. He was incurable.

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00:10:04,802 --> 00:10:07,803

But that doesn't mean say you can't help people.

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00:10:07,803 --> 00:10:11,804

John Merrick lived for three years at the London Hospital.

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00:10:11,804 --> 00:10:19,806

Dr. Treves visited him often, constantly bringing books which opened up a magic world of make-believe to his patient.

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00:10:19,806 --> 00:10:24,807

Who began to construct miniatures which he proudly presented to visitors.

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00:10:24,807 --> 00:10:33,809

He must have had the most horrific mental troubles to bear knowing what he looked like.

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00:10:33,809 --> 00:10:39,810

I believe that his coming into our hospital helped not only himself but all those around us.

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00:10:39,810 --> 00:10:43,811

It widened our own experience. It certainly widened mine.

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00:10:43,811 --> 00:10:47,812

And in the end I felt rather ashamed of my initial reaction.

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00:10:47,812 --> 00:10:53,813

The circumstances of John Merrick's death were a little puzzling to us at the time.

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00:10:53,813 --> 00:11:03,816

You see, John Merrick because of the size of his head had to sleep sitting up with his head resting on his knees.

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00:11:03,816 --> 00:11:10,817

When we found him he was lying flat on the bed and as a consequence he'd suffocate it.

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00:11:10,817 --> 00:11:22,820

Now whether it was a deliberate act of suicide or whether it was a pathetic attempt on his part to try to live some sort of a normal life

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00:11:22,820 --> 00:11:26,821

and sleep like a normal human being we will never know.

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00:11:26,821 --> 00:11:29,822

But he was dead when we found him.

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00:11:29,822 --> 00:11:34,823

And although it was tragic and he'd made many friends while he was here at the London Hospital

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00:11:34,823 --> 00:11:45,825

I felt that we'd made the last few years of his life a little better than it would have been if he'd remained where he was.

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00:11:45,825 --> 00:11:51,827

When John Merrick, the elephant man, died he was thought to be a singular hideous aberration of nature.

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00:11:51,827 --> 00:12:00,829

Yet today 100,000 people in the United States alone are victims of the elephant man disorder neurofibromatosis.

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00:12:00,829 --> 00:12:06,830

It is John Merrick's suffering that has called attention to their affliction, something society has tried to hide.

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00:12:06,830 --> 00:12:11,832

How does anyone afflicted with this disorder cope with it today?

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00:12:11,832 --> 00:12:18,833

The elephant man's disorder is discussed by Dr. Alan Rubenstein.

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00:12:18,833 --> 00:12:23,834

John Merrick, who was the elephant man, had an extraordinary case of neurofibromatosis

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00:12:23,834 --> 00:12:28,835

with extensive overgrowth of tissues surrounding the neurofibromas.

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00:12:28,835 --> 00:12:33,837

He really represents one end of a wide spectrum of this disorder.

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00:12:33,837 --> 00:12:44,839

The disorder can range from a benign syndrome in which only a few lesions are present to people who have more severe involvement of the skin

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00:12:44,839 --> 00:12:55,842

and more seriously growths of deeper areas of the body, which can lead to blindness, deafness, and spinal cord paralysis.

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00:12:55,842 --> 00:13:01,843

Neurofibromatosis is not a rare disorder. The incidence is approximately 50 per 100,000,

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00:13:01,843 --> 00:13:05,844

which means that 100,000 Americans are affected with this disorder.

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00:13:05,844 --> 00:13:14,846

That makes it as common as muscular dystrophy or multiple sclerosis or other diseases which many people have heard of.

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00:13:14,846 --> 00:13:22,848

I started to get panic when I was about my 20s, my late 20s, and I suddenly realized that something wasn't quite right.

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00:13:22,848 --> 00:13:25,849

Irene Smith has additional symptoms.

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00:13:26,849 --> 00:13:32,850

Then I started to get falling about losing my sense of balance.

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00:13:32,850 --> 00:13:39,852

They x-rayed my head and they said I've got one groin on the eight cranial nerve at the head,

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00:13:39,852 --> 00:13:44,853

which is obviously going to throw me off my balance and there's also one in my right ear.

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00:13:44,853 --> 00:13:47,854

And that would also help me to lose my sense of balance.

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00:13:47,854 --> 00:13:53,855

I never know when I'm going to fall. I can be standing on the curb, going to take a step forward, and I'm flat on my face.

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00:13:53,855 --> 00:13:57,856

When you go into a dress shop, you don't want the assistant in the cubicle with you,

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00:13:57,856 --> 00:13:59,857

so you say no thank you, I can manage on my own.

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00:13:59,857 --> 00:14:04,858

Because you feel very embarrassed in case they think their dresses might be contaminated or something like that.

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00:14:04,858 --> 00:14:07,858

And I'm very careful how I choose my dresses.

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00:14:07,858 --> 00:14:14,860

I always make sure that I never buy a sleeveless dress or a see-through blouse or anything with a plunging neckline.

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00:14:14,860 --> 00:14:20,861

Always make sure that my arms are either half covered or fully covered if I can.

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00:14:20,861 --> 00:14:26,863

It's not always possible to get the clothes that you want and I don't make my own clothes.

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00:14:26,863 --> 00:14:30,864

Otherwise I would always make a go around dress like a nun.

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00:14:30,864 --> 00:14:36,865

Just because that's how you feel that you want to cover yourself up as much as possible.

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00:14:36,865 --> 00:14:44,867

This 58-year-old man who demonstrates the most common lesion in neurofibromatosis, which is the dermal neurofibroma,

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00:14:44,867 --> 00:14:57,870

they are usually multiple, more common on the torso, and usually break the skin and present as multiple nodules which are usually painless.

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00:14:57,870 --> 00:15:02,871

They can range in number from a few to literally thousands.

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00:15:02,871 --> 00:15:09,873

These lesions are composed of nerve cells and fibrous tissue, hence the term neurofibroma.

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00:15:09,873 --> 00:15:17,875

The disorder is genetic. It's a function of an abnormality in the chromosomes of an individual.

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00:15:17,875 --> 00:15:23,876

The precise location of the abnormality and how to identify it are as yet undetermined.

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00:15:23,876 --> 00:15:26,877

Plastic surgery is a partial answer.

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00:15:26,877 --> 00:15:34,879

Over the past several years we've done dozens of surgical procedures in which patients under general anesthesia

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00:15:34,879 --> 00:15:41,880

have extensive removal of his skin lesions, and the results in general have been quite good.

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00:15:41,880 --> 00:15:47,882

I used to have many large ones, similar to those that I have on my body, on my face.

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00:15:47,882 --> 00:16:00,885

And the foundation had a doctor, Simon, a plastic surgeon, and he removed them and it really picked me up a lot, changed my attitude a lot.

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00:16:00,885 --> 00:16:12,887

As a social worker my primary concern is the impact of a genetic neurological disorder on patients and families' lives.

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00:16:12,887 --> 00:16:21,889

And one of the things that the NF Patient Family Group tries to do is to provide an atmosphere to talk about how they feel.

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00:16:21,889 --> 00:16:23,890

Do people ever say nasty things to you?

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00:16:23,890 --> 00:16:36,893

No, nobody has ever said anything nasty to me, but I do know that people just are continually staring and eventually, if the stare lasts for more than 5 or 10 seconds, you eventually do feel extremely self-conscious.

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00:16:36,893 --> 00:16:48,896

I always had a very large, big red, floppy tumor on my left shoulder that I had had since birth and as I was growing older the tumor itself developed and grew.

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00:16:48,896 --> 00:17:05,900

And to that point I was very self-conscious about it, and when I used to go to the beach or any other place like that during the summer where you could indeed go topless, I would always be very conscious of that and wear a very dark shirt so that the tumor would not show through.

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00:17:05,900 --> 00:17:23,904

My main area of frustration and concern is lack of knowledge on the part of physicians. I've known for some time what I have, but the physicians with whom I spoke and my family history all seemed to indicate that it was nothing more than neurofibromas.

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00:17:23,904 --> 00:17:28,905

It wasn't to our two sons we're born that I realized it was much more.

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00:17:28,905 --> 00:17:31,906

One doctor said to me, it's no big deal.

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00:17:31,906 --> 00:17:39,908

I look at my son, he has tumors and I feel so helpless not being able to do anything.

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00:17:39,908 --> 00:17:47,909

And at one point I was getting upset over watching these tumors come out and not knowing how many or where they're going to hit.

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00:17:47,909 --> 00:17:52,911

Now I pray that they don't hit in the vital areas.

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00:17:52,911 --> 00:17:54,911

It is totally unpredictable.

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00:17:54,911 --> 00:18:06,914

He has his years ahead of him where he has his puberty, he has his 20s to go through, his 30s. Nobody can tell me.

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00:18:06,914 --> 00:18:11,915

And I can sit back and say, dear God help me, there's nothing you can do.

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00:18:11,915 --> 00:18:22,917

When the elephant man was playing in town, someone looked at me, a young boy, and looked at his friend and said, hi, there's Mrs. Merrick.

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00:18:22,917 --> 00:18:26,918

All of us know how important touch is.

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00:18:26,918 --> 00:18:33,920

When people touch you, you know, like that, how does it feel? Does it hurt physically sometimes?

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00:18:33,920 --> 00:18:38,921

Yes, it hurts when they touch me. It depends where they touch me or how hard they touch me, it hurts.

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00:18:38,921 --> 00:18:45,923

Sometimes I want to hug somebody, but looking like I am, I'm afraid to because I don't know how they will react.

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00:18:45,923 --> 00:18:47,923

What are you afraid of happening, Porter?

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00:18:47,923 --> 00:18:53,925

They will be repulsed. I've had people look at me and back away in horror.

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00:18:53,925 --> 00:18:59,926

You know, it might not only be that they may feel repulsed, but they might feel that it's contagious, but it's not.

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00:18:59,926 --> 00:19:06,928

Like when we have a social gathering and people come in and they kiss each other, like I always kind of wait for them to approach me first.

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00:19:06,928 --> 00:19:14,930

And if I see them approach me, then I will, I can already tell the sign. If they're going to approach me, if they don't, I'll just give them a smile and that make them feel uncomfortable.

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00:19:14,930 --> 00:19:24,932

I have a different perspective. I'm a parent. I don't have NF myself, but as I was listening to you and to Porter and to June before, and especially to June before,

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00:19:24,932 --> 00:19:32,934

I had another thought and it was that all of us, my daughter and you and June and Porter are bigger than NF.

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00:19:32,934 --> 00:19:37,935

And that's not the same thing as saying that it's nothing much. It is a great deal.

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00:19:37,935 --> 00:19:46,937

But I know that if I give in to the anxiety, I could not live a contributing, happy life and my daughter can't either.

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00:19:46,937 --> 00:19:57,940

And so you have to go beyond that. My daughter is more than her neurofibromatosis. All of us are. And the fact that we are here and functioning and working shows this.

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00:19:59,940 --> 00:20:02,941

The Legacy of the Elephant Man

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00:20:03,941 --> 00:20:09,942

The tragic life of the Elephant Man has attracted the attention of the world to his disorder.

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00:20:09,942 --> 00:20:17,944

The importance of research on neurofibromatosis extends far beyond the fact that 100,000 people have this disorder.

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00:20:17,944 --> 00:20:31,947

The incidence of mental retardation, epilepsy and cancer, three very common health problems in the United States, are much higher in people with neurofibromatosis than in the normal population.

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00:20:31,947 --> 00:20:44,950

Research on the mechanisms by which neurofibromatosis produces these problems may very well lead clues to clues about these other major health problems.

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00:20:44,950 --> 00:20:47,951

The first purpose is to provide information.

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00:20:47,951 --> 00:20:51,952

Joan Rudd is president of the National Neurofibromatosis Foundation.

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00:20:51,952 --> 00:20:59,954

In the 100 years since Dr. von Recklinghausen first described neurofibromatosis, scant little has been learned about the disorder.

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00:20:59,954 --> 00:21:13,957

Whatever progress, whatever information was learned about neurological diseases in general, there was no way for communication to be promoted internationally readily.

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00:21:13,957 --> 00:21:16,958

The foundation seems to have filled that need.

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00:21:16,958 --> 00:21:23,959

Doctors from all over the country and all over the world in all specialties have a structure within which to communicate.

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00:21:23,959 --> 00:21:36,962

For information concerning neurofibromatosis, write NF-180 Riverside Drive, New York, New York 10024.

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00:21:53,966 --> 00:21:55,967

As we go in search of the unusual.

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00:21:55,967 --> 00:21:59,968

A man was swimming across the river and this great serpent appeared.

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00:21:59,968 --> 00:22:01,968

Facts or fiction.

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00:22:01,968 --> 00:22:03,969

Their bodies were buried into the wall.

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00:22:03,969 --> 00:22:05,969

Natural or supernatural.

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00:22:05,969 --> 00:22:09,970

Two flying objects collided in space over Death Valley.

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00:22:09,970 --> 00:22:14,971

And in search of Historyathon, all day today on the History Channel.