

PACESETTERS INVESTIGATES THE PLIGHT OF BRITAIN'S 3,000 VICTIMS OF 'THE ROYAL DISEASE'

ONCE or twice a week Mrs GRO-A performs a minor miracle.

She reaches into the fridge, gets out a bottle of coagulant, and gives her seven-year-old son, GRO-A, a blood transfusion. GRO-A who lives in GRO-A is one of Britain's 3,000 haemophiliacs—people whose blood will not clot properly.

Most are males, who inherited the disease from their mothers.

A vital factor is missing from their blood, which means that every little bump or scratch could make them bleed to death.

Haemophilia used to be called "the royal disease," because European royalty carried the strain for centuries.

Queen Victoria's son, Leopold was a victim. Her daughters, Alice and Beatrice, passed it on to their children.

GRO-A is lucky.

Two years ago, GRO-A, 30, was specially trained by staff at London's Great Ormond Street hospital to give him the life-saving transfusions of the blood coagulant, Factor 9. Any little bump causes internal bleeding.

and GRO-A may need a transfusion every five or six days.

GRO-A says: "I always keep six bottles on hand next to the hamburgers. GRO-A loves hamburgers for his tea."

Hurts

"Sometimes it's difficult to find a vein in his arm and I have to try more

GRO-A

# 's Mum saves his life every few days

By John Spencer

than once. Then GRO-A says 'Mummy you're hurting.' It's terrible for him.

"It hurts me too. I'm teaching him now to give himself the transfusions, so that when he's a little older he'll be able to cope by himself."

When GRO-A was born, GRO-A had never heard of haemophilia.

She says: "He seemed a

normal baby, until three months when I noticed these huge bruises appearing on his legs. They seemed to come from nowhere, just while he was lying in his cot.

"I was told by a doctor that the bruising meant haemophilia, and that it was always passed down through the female line.

"I felt frightened. And guilty.

Fault

"It must be my fault that my baby would face a lifetime of suffering."

What mother wouldn't feel the same? Eighteen months after GRO-A arrived, GRO-A was sterilised.

Though women carry the disease, they rarely suffer from it. GRO-A took the right step, because a healthy daughter born to her would have, in time, produced a haemophiliac son.

About a third of haemophilia cases occur spontaneously. And the genes

of both parents play a part.

The other two-thirds of haemophiliacs inherit the disease.

One male in every 10,000 is affected.

The first two years of GRO-A's life were heart-breaking for her.

For two years, she never left him, rarely taking him out. He wore a special helmet to protect his head.

When she noticed the tell-tale swellings that meant GRO-A was bleeding internally she went into her emergency routine.

She says: "I phoned for an ambulance to Brighton station where there was always a compartment reserved for us on the London train.

Play

"At the other end, another ambulance would be standing by to rush us to the hospital."

When GRO-A was three, GRO-A and GRO-A made a hard decision.

GRO-A says: "We decided that there would be no life at all for GRO-A if we cosseted him and protected him for ever."

"We bought him a bike and encouraged him to play with other kids.

Freedom for GRO-A means super-organisation for GRO-A and her husband.

As supplies of blood run low, GRO-A's engineer dad, 36-year-old GRO-A, picks up more on his way home from his London office.

GRO-A

GRO-A and GRO-A

The boy goes to a private school — GRO-A. Corporation refused him a place at a State primary school.

GRO-A has a part-time job. GRO-A.

Label

But she is ready at a moment's notice to dash home and get her transfusion equipment.

If she has to go somewhere special after work, she pins a label on

GRO-A's jacket with her phone number on it.

Last weekend, GRO-A took GRO-A to a local model aeroplane club. A heavy plane went out of control and smashed into GRO-A's legs, slicing through his Wellingtons.

GRO-A has given him five transfusions so far—"Watching my child suffer is sheer agony," she says.

"And so is answering his questions. The saddest part is that he is such a bright, intelligent, active little boy."

## COST OF LIVING

BOTH blood coagulants—Factor 8 and Factor 9—can cost £25 to £100 for each injection.

The cost depends on how much coagulant is needed to stop blood flowing.

Because only 10 per cent of the patients need Factor 9 the National Health Service can buy enough to go round. But far too many sufferers

need Factor 8. And there is simply not enough money available to buy it for them.

If you live very far from the nearest hospital that can cope with haemophilia, you may be lucky enough to have arrangements made for blood coagulant transfusions in your home.

But most haemophiliacs are still without this

new treatment—introduced three years ago.

They still have to make do with the old-fashioned blood plasma treatment—simple replacement of blood.

Great Ormond Street Hospital estimates that it would cost £36,000 a year to treat just 10 sufferers.

They have 80 haemophilia patients registered—and a budget of only £24,000 for treating them.