

WOLF HIRSCHHORN SYNDROME TRUST

**THE WOLF HIRSCHHORN
SYNDROME TRUST** was formed on
5th May 1994.

We are a national registered charity
and our objectives are:

- To collate and share knowledge, assist and advise parents/carers, professionals and other persons associated with Wolf Hirschhorn Syndrome.
- To promote research (and to make the results of the research available) into the development or needs and treatment of persons with Wolf Hirschhorn Syndrome and into ways in which they may be most effectively assisted, so as to improve their quality of life and develop their full potential.
- To organise activities for the benefit of persons with Wolf Hirschhorn Syndrome and their parents/carers resident in the United Kingdom.

WHEN WAS WOLF HIRSCHHORN SYNDROME FIRST RECOGNISED?

In 1964 it was first recognised by two German Geneticists by the names of Wolf and Hirschhorn.

The oldest person with Wolf Hirschhorn Syndrome in the United Kingdom was born in the United Kingdom in 1962.

IS WOLF HIRSCHHORN SYNDROME HEREDITARY?

Yes, if one or both parents have translocated chromosomes. It is not

only transmitted this way, it can occur spontaneously during conception.

WHAT IS A GENETIC DISORDER?

Wolf Hirschhorn Syndrome is a rare genetic disorder. We all have 23 pairs of chromosomes in every cell in our body. One chromosome of each pair is passed down from our mother and the other from our father.

4p-

Charity	Registration	No.
1038319		

The top portion of the chromosome is called "p" and the bottom "q".

Persons with Wolf Hirschhorn Syndrome have all or part of the "p" section of the 4th chromosome missing. This consequently results in the alternative name of 4p-.

IS THERE A CURE?

There is no known cure. There is nothing anyone can do to prevent Wolf Hirschhorn Syndrome from occurring.

CAN TESTS BE CARRIED OUT TO DETECT WOLF HIRSCH HORN SYNDROME?

Tests can sometimes be carried out during pregnancy, but the risks of miscarriage or damage are very high.

A simple blood test after birth can usually diagnose the disorder.

CARE

Persons with Wolf Hirschhorn Syndrome require care on a 24-hour basis.

Providing this care is extremely demanding on parents/carers and

although rewarding, can be very stressful.

THE NEED

To achieve our aim, the Trust desperately needs funds to provide specialist equipment for persons with Wolf Hirschhorn Syndrome as well as printing costs involved in providing practical advice, booklets and informative literature.

HOW IS DEVELOPMENT AFFECTED?

Every person with Wolf Hirschhorn Syndrome has unique characteristics, although they do share a number of similar features. There are no two cases alike.

The most common characteristics/features are:

Growth retardation – weight gain is difficult

Lax muscle tone

Recurrent respiratory infections

Seizures/convulsions

Small birth weight

Hypospadias in males

Feeding problems – some persons are fed by nasal gastric or gastrostomy tube in liquid form. Others cannot chew

Mild to profound developmental delay both physically and mentally – progress is very slow

Long slender bodies and limbs

Cleft lip and palate

Heart problems

Communication difficulties

Little or no speech.

HOW CAN YOU HELP?

PAYROLL GIVING – Ask your employer to name us as a Charity through the Payroll Giving Scheme.

DEED OF COVENANT – for everyone who pays Income Tax, a Covenanted Gift over a minimum of three years, benefits the Trust in that we can recover the Income Tax on the amount of your payment at no extra cost to you..

DONATIONS – all donations, however small, are most gratefully received.

LEGACY – please seriously consider remembering the Wolf Hirschhorn Syndrome Trust in your Will and suggest to others to do likewise. Gifts to Charities are free from Inheritance Tax..

GIFT AID – on individual gifts the Trust can recover the Tax paid. Using Gift Aid means that for every pound that you give, the charity gets an extra 28 pence from the Inland Revenue, helping your donation go further. Gift Aid allows the charity to reclaim the basis rate of income tax you've paid on the donation. If you're a taxpayer, this means that £100 can be turned into £128 just so long as donations are made through Gift Aid. Imagine what a difference that could make, and it doesn't cost you a thing.

On top of that, if you're a higher rate taxpayer, you can claim further tax relief on the donation in your annual tax return.

FOR FURTHER INFORMATION, PLEASE CONTACT:

MRS CHRISTINE HILDER
FOUNDER
WOLF HIRSCHHORN SYNDROME
SUPPORT GROUP AND WOLF
HIRSCHHORN SYNDROME TRUST
2B HARVESTERS CLOSE
RAINHAM
KENT ME8 8PA

TEL: 01634 264816

OR

MR ALASDAIR MILLAR
THE TREASURER
WOLF HIRSCHHORN SYNDROME
TRUST

1 MONTGOMERY CRESCENT
DUNBLANE
PERTSHIRE FK15 9FB

OR

MR TED BULMER
NATIONAL CO-ORDINATOR
WOLF HIRSCHHORN SYNDROME
SUPPORT GROUP
1 HAWTHORN VILLAS
HOLMES CHAPEL
CHESHIRE CW4 7AR

TEL: 01477 549465

OR

MRS SHONA WALLACE
TRUSTEE
WOLF HIRSCHHORN SYNDROME
TRUST
BUNGALOW 2
PETTYCUR BAY CARAVAN PARK
KINGHORN
FIFE KY3 9YE

OR

MRS MARGARET BEGENT
TRUSTEE
WOLF HIRSCHHORN SYNDROME
TRUST
62 HARWOOD AVENUE
HORNCHURCH
ESSEX RM11 2NW