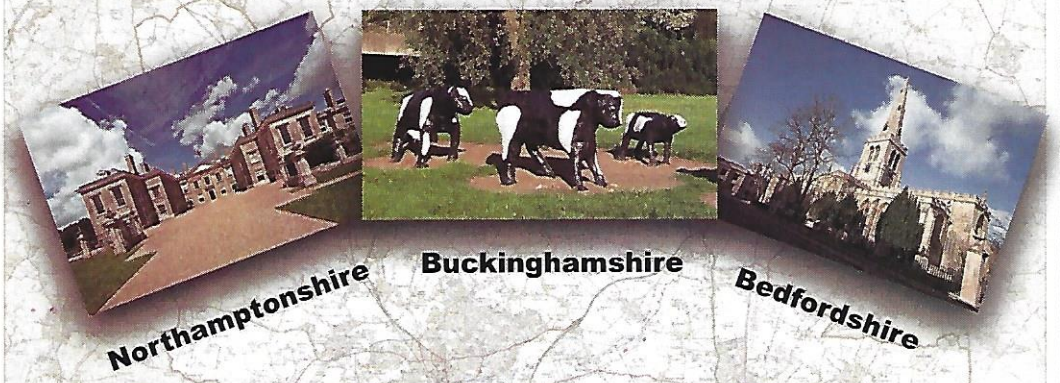
Tri Counties for Trisomy



Northamptonshire Buckinghamshire Bedfordshire

Free BBQ at end of the run

Min. Donation of £10 to Soft UK

SOFT UK
Support Organisation for Trisomy 13/18

Save the Date

Sunday 13th August 2023

Our Grandson Ben was diagnosed with Trisomy 13 (Patau's Syndrome) at 31 weeks and 3 days and his Mummy & Daddy were advised that he would unlikely have survived the rest of the pregnancy and almost certainly not the birth. They decided on a Termination for Medical Reasons (TMFR) to stop his suffering. It was the hardest decision that any parent should have to make and **SOFT UK** are the Charity that helped them (and still help them) with their bereavement. Ben was born on 3rd February 2022. SOFT advise, and help, Grandparents too so that we can help.

There is no cure for a chromosome disorder, this would have occurred at the moment of conception. Please take some time and read the below to learn a little about the Syndrome.

Our car run in aid of SOFT UK will take place on Sunday August 13th (for Trisomy 13)

Thank you, Martin & Jackie

Trisomy 13 (Patau's) Syndrome is a rare chromosomal disorder in which all or a portion of chromosome 13 appears three times (trisomy) rather than twice in cells of the body. In some affected individuals, only a percentage of cells may contain the extra 13th chromosome (mosaicism), whereas other cells contain the normal chromosomal pair.

Such abnormalities may include developmental delays, profound mental retardation, unusually small eyes (microphthalmia), an abnormal groove in the upper lip (cleft lip), incomplete closure of the roof of the mouth (cleft palate), undescended testes in affected males, and extra fingers and toes Additional malformations of the head and facial area may also be present, such as a relatively small head with a sloping forehead; a broad, flat nose; widely set eyes vertical skin folds covering the eyes; inner corners (epicanthal folds); scalp defects; and malformed, low-set ears. Affected infants may also have incomplete development of certain regions of the brain (e.g., the forebrain); kidney malformations; and structural heart defects at birth. For example, characteristic heart defects may include an abnormal opening in the partition dividing the upper or lower chambers of the heart or persistence of the fetal opening between the two major arteries emerging from the heart Many infants with Trisomy 13 Syndrome fail to grow and gain weight at the expected rate and have severe feeding difficulties, diminished muscle tone (hypotonia), and episodes in which there is temporary cessation of spontaneous breathing