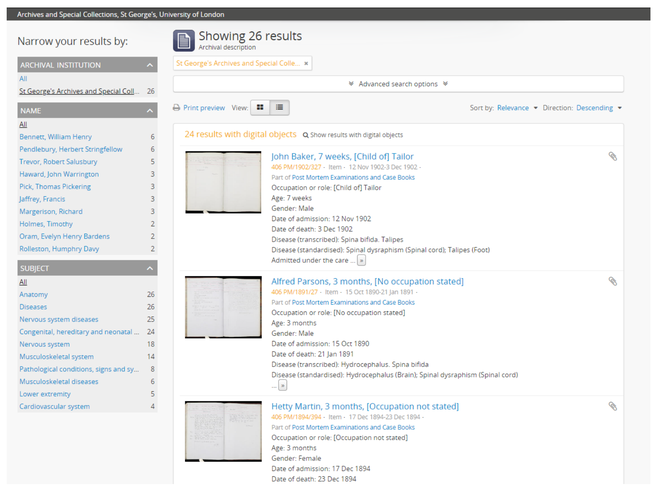
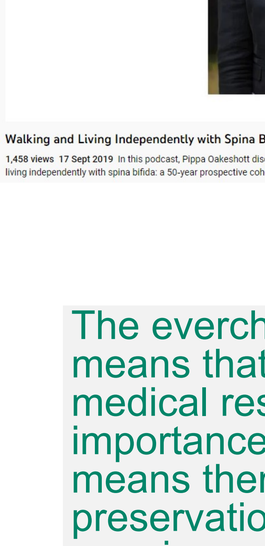
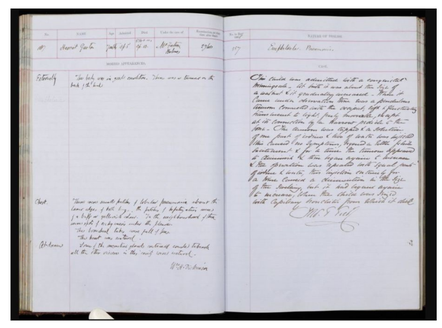
Exploration of disease past and present: spina bifida

As far back as the 1860s St George's demonstrated excellence in understanding and treating a rare but lifelong birth defect called spina bifida.

Spina bifida occurs when a baby's spine and spinal cord does not develop properly in the womb, causing a gap in the spine (NHS, 2020). Most babies born with spina bifida can have surgery to close the opening in the spine, however, their nervous system will have already been damaged which can lead to a range of health problems. Some may also have learning disabilities.





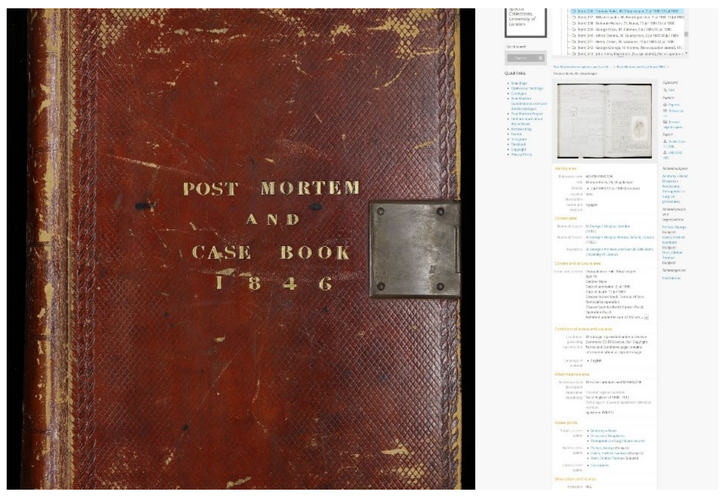


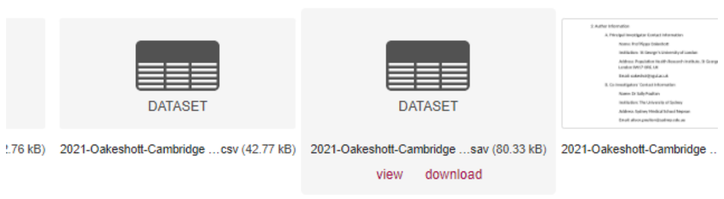
III. A CASE OF MENINGOCELE, IN THE OCCIPITAL REGION,

WHICH WAS INJECTED WITH IODINE, WITHOUT ILL CONSEQUENCES, THE PATIENT DYING OF BRONCHO-PNEUMONIA.

I HAVE thought that the following case would be of interest (although, perhaps, the treatment did not lead to any definite result), since the disease is a rare one, and attempts to arrest its progress by any operation have been still rarer. In the instance before us, that attempt proved unsuccessful, although many of the elements necessary for success were present; nor were there the contra-indications to operative interference which we so commonly meet with in this malformation. There was, however, one unfavourable symptom which made me look on the case with doubt from the commencement, and which would have rendered ultimate success very doubtful, even had the fatal complication of broncho-pneumonia not intervened. I mean, the existence of internal

St George's Hospital Report v.1 1866. Public Domain. HathiTrust Digital Library. http://bitly.ws/w4Nu





What do our records look like…

Our digitised Post Mortem Examinations and Case Books contain numerous of cases of spina bifida in infants aged between 3 days and 1 year, demonstrating how quickly babies' health deteriorated without surgery in the past.

The Cambridge Cohort of Open Spina Bifida is a unique spina bifida data resource that provides detailed data on the health and quality of life of 114 individuals born with spina bifida. The resource is rare in that it includes a detailed neurological examination at birth, and follows up on participants throughout their lives, with 99% follow-up to the mean age of 50 years.

It is important to have continued access to historical and current information about spina bifida to trace our past and present understanding of the disease and its treatment. These act as building blocks for current and future research, and document St George's role in research and treatment over time.

The everchanging technical landscape means that digital records essential for medical research are at risk. The importance of our digital records means there is a need for digital preservation to ensure these records remain accessible to protect our knowledge and investment, and to ensure future generations of students and researchers can access the knowledge contained within.

By actively managing our records and data and applying preservation tools and activities we are able to maintain the record and data's ongoing viability. The steps we take now to protect our digital records will ensure their longevity.

St George's, University of London's mission is to pursue excellence in academic medicine, healthcare and science, informed by a global outlook by creating and sharing knowledge. By identifying records for digital preservation, we ensure their availability for good, forever, and that the data contained within is available to all.

Access the Cambridge Cohort of Open Spina Bifida here:

SCAN ME http://bitly.ws/w45w

Access our digital Post Mortem cases here:

SCAN ME http://bitly.ws/w45Y

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