# Registry for congenital upper limb anomalies in Prince of Wales Hospital, Hong Kong: abridged secondary publication

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## KEY MESSAGES

1. As of July 2023, a total of 1891 records of congenital upper limb anomalies (CULAs) had been collected.
2. The first registry of CULAs in Hong Kong can be used for investigating the epidemiology of these anomalies, identifying risk factors, and improving healthcare planning and delivery.
3. Existing data regarding general functional and aesthetic outcomes after surgical treatment provide valuable insights into immediate improvements.
4. Continued data collection, analysis, and collaboration among stakeholders will enhance our ability to prevent, diagnose, and manage CULAs.

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## Introduction

Congenital upper limb anomalies (CULAs) significantly affect a child's physical and psychological development. More than 100 CULAs have been classified,[1] ranging from trigger thumb and simple accessory nubbins to complex syndactyly, hypoplastic thumb, multiple hereditary exostoses, constriction band syndrome, and duplicated thumbs. The incidence and prevalence of CULA conditions vary among ethnicities and geographical regions. We aimed to develop the first CULA registry in Hong Kong, based on patients presenting to Prince of Wales Hospital since 1984.

## Methods

The registry was implemented in February 2020; data were collected both prospectively and retrospectively. Exclusion criteria were traumatic injuries or lesions not associated with CULA conditions, pre-existing CULA presented to the orthopaedic or hand clinic for non-CULA conditions, and CULAs lacking assessment or treatment at Prince of Wales Hospital.

Data collected included patient demographics, diagnosis, laterality of upper limb involvement, hand dominance, family history, associated non-upper limb anomalies, and occupational therapy assessment records, as well as radiographic findings, operations, and surgical treatment details. Patients were classified according to three systems: (1) the International Federation of Societies for Surgery of the Hand, (2) the Japanese Society for Surgery of the Hand, and (3) the Oberg, Manske, and Tonkin classification. The registry system was developed and maintained by a professional information technology service using MSSQL, .NET Core, and Vue.js.

## Results

As of June 2023, 2332 patients had presented to the CULA clinic. Of these, 1891 (81.1%) were congenital cases and thus included; the remaining 441 (18.9%) presented with injuries or lesions not associated with CULA (ie, non-congenital) and were thus excluded.

Of the 1891 CULA records, 1070 (56.6%) involved male patients and 821 (43.4%) involved female patients. The registry was designed to capture up to three upper limb anomalies per patient. Among these, 194 (10.3%) patients had two anomalies and 26 (1.4%) had three anomalies.

The highest number of new CULA patients presenting to the clinic was 100 in 2006, followed by 84 in 2019 and 81 in 2018 (Fig 1). The three most frequently documented birth years were 1994 (n=73), 1995 (n=63), and 2017 (n=62) [Fig 1]. The age at first visit was most frequently within the first 2 years of life; 1068 (56.5%) patients presented before 1 year of age, whereas 231 (12.2%) presented between 1 and 2 years of age. The mean±standard deviation age at first presentation was 4.5±6.8 (range, 0.1-60.1) years. At the last follow-up,

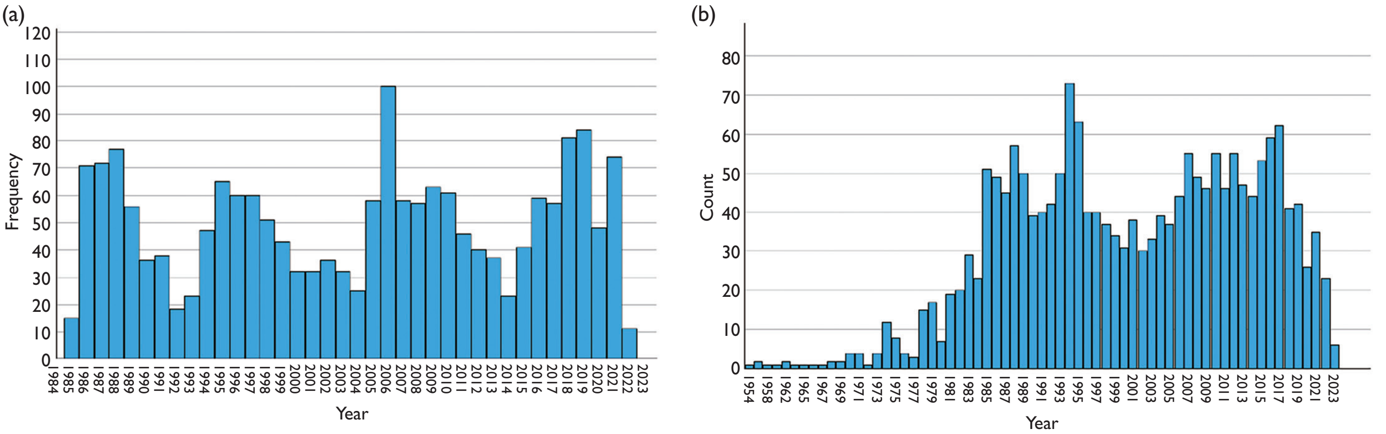

FIG 1. Frequency distributions of (a) new patients registered and (b) birth years of patients with congenital upper limb anomalies.

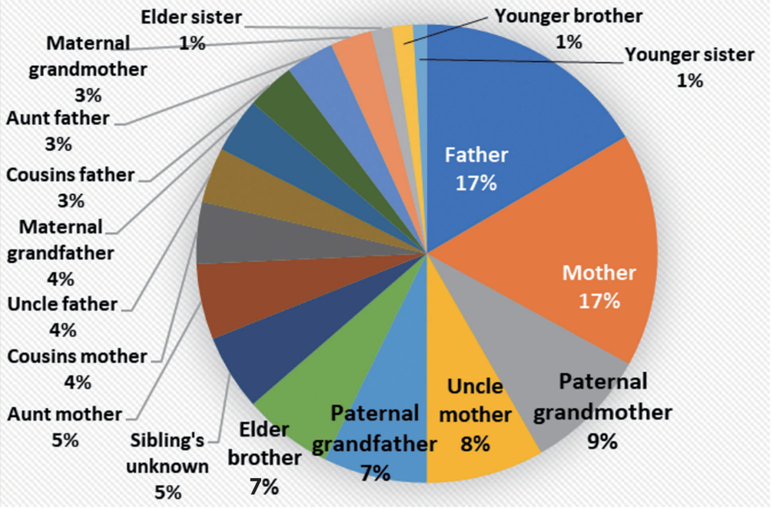

FIG 2. Breakdown of relatives affected among patients with a family history.

among 1522 patients, 117 (7.7%) were aged 0 to 1 year, 761 (50.0%) were aged 1 to 10 years, 466 (30.6%) were aged 10 to 20 years, and 178 (11.7%) were aged >20 years. The mean±standard deviation age was 9.5±8.8 (range, 0.1-61.35) years.

In total, 146 (7.7%) patients reported a family history of CULA, involving 212 affected relatives, including the father (17.0%, n=36), mother (16.5%, n=35), paternal grandmother (8.5%, n=18), uncle's mother (8.0%, n=17), and elder brother (6.6%, n=14) [Fig 2].

The three most common presentations were duplicated thumb (n=1128-1138), trigger thumb (n=456-511), and clasped thumb (n=212-213), depending on the classification system used. Among patients with a second anomaly, the most frequent conditions were clinodactyly (n=54-55), syndactyly (n=34-40), and hypoplastic thumb (n=13).

## Discussion

We developed the first CULA registry in Hong Kong, based on patients who presented to the Prince of Wales Hospital between 1984 and 2023. As of June 2023, 1891 patients with CULA were included. Our registry spans almost 40 years, exceeding the 18-year duration of the New York Congenital Malformations Registry.[2] In comparison, a Korean registry included >10 000 patients aged >9 years,[3] but data were recorded for only four CULA conditions. In contrast, our registry comprehensively documents all CULA conditions using three classification systems. Additionally, it includes multimedia records such as photographs, videos, and radiological images.

Although the mean age at first presentation was 4.6 years, almost half of the patients were examined within their first year of life. The birth years of patients peaked in 1994 and 1995 and then declined in 1999 and the following few years, as well as in more recent years. These trends may correspond to reductions in birth rates during the same periods in Hong Kong. The subsequent rise in presentations around 2008 may reflect an increase in birth rates associated with a higher number of pregnant women arriving from Mainland China, many of whom had little or no prenatal screening. There appears to be a steady incidence of congenital anomalies; no major events (eg, introduction of new teratogens) have been identified over the past four decades. There was also no evidence of increased referrals from other districts or across the border.

The three most common conditions were duplicated thumb, trigger thumb, and clasped thumb. Almost all patients with duplicated thumbs underwent early surgery. Many required additional procedures as they grew, owing to subsequent joint laxity, deformity, or stiffness. Patients with trigger or clasped thumbs underwent fewer operations but often required intensive allied health support, including mobilisation exercises and splinting. The health burden varied among patients.

## Conclusion

The establishment of the first CULA registry in Hong Kong facilitates investigation of the epidemiology of these conditions, identification of risk factors, and healthcare planning and delivery. It also provides a foundation for future research, multidisciplinary collaboration, policy development, and patient empowerment.

## Funding

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## Disclosure

The results of this research have been previously published in:
1. An educational booklet titled *Congenital Upper Limb Anomalies/Differences* and website covering the major CULA is designed and distributed to the patients and their parents.

### References

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