Challenges in handling congenital anomalies clusters: a recent mediatic example in France

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Issue:
In 2018 in France, reports of aggregated cases of isolated transverse limb reduction defects, a rare congenital anomaly (1.7 for 10,000 total births) generated a large mediatic interest with environmental factors overtly pointed out. Our aim is to describe the investigations carried out and to share the challenges we met.

Description of the response:
Over a period of 5 years (2010-2015), 3 aggregates were signaled by health professionals in 3 different areas in France. Investigations included case ascertainment, epidemiological analyses, and search for a common exposure. Standardized Incidence Ratios were computed using the 6 French registries's data as reference. In one area, the local registry performed a concurrent analysis using satscan. Parents filled a questionnaire addressing environmental and occupational exposures. Environmental databases were consulted as well as animal health surveillance data.

Results:
Fourteen cases met the case definition. The excess of cases was ascertained in two aggregates located in a two small towns in the western part of France and comprising respectively 3 children born in 2007-2008 (SIR: 87.8 CI95%:[17-256]) and 4 children born in 2011-2013 (79.8 [2.5-204.2]). The third signal included 7 cases born between 2009 and 2014 residing in 7 towns located above the Alps and did not yield a significant excess when related to expected cases in the administrative subdivision (0.94 [0.38-1.95]). The concurrent analysis found a significant excess, generating a lengthy debate. None of the investigations identified a common cause or notable exposure. Delayed feedback and negative conclusions led to incomprehension among families.

Lessons:
Informing stakeholders timely is crucial but communicating effectively about methods used and negative results can be challenging.

Key messages:
- Congenital anomalies clusters are sensitive topics.
- Cluster investigations involve a scientific and a societal component that must both be taken into account in organizing the public health response.