



## Monthly Newsletter From the International Clearinghouse

October 2014

Issue 2014 - 10

### What's Going on Regarding Birth Defects

October is National Down Syndrome Awareness Month in United States. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) will feature a number of activities throughout the month of October to raise awareness about Down syndrome:

- **Web feature:** a special web [feature](#) on National Down Syndrome Awareness Month highlighting Keaton's story is posted on the CDC Features page at [www.cdc.gov/features](http://www.cdc.gov/features).
- **New research:** A recent article published on Birth Defects Research-A examined the differences in hospital resource use between children with Down syndrome and another major birth defect, mainly congenital heart defects, and children with Down syndrome who did not have another major birth defect. This [study](#) provides useful information for evaluating patterns of hospital resource use and associated costs for children with Down syndrome. Read the Key Findings to the article here: <http://www.cdc.gov/ncbddd/birthdefects/downsyndrome/features/hospital-cost-downsyndrome.html>
- **Social media:** tweeting at [https://twitter.com/CDC\\_NCBDDD](https://twitter.com/CDC_NCBDDD). Please comment, re-post, re-tweet and follow [@CDC\\_NCBDDD](#). #DSAM2014 is also be used in all of Down syndrome awareness tweets throughout October.

### News from Programs

Ignacio Zarante, G11 ECLAMC hospital, Pontificia Universidad Javeriana in Bogota, summarized the statistics of visits to photographic **ECLAMC Atlas** in its first 17 months (May 2013 to August 2014). The ECLAMC Atlas of congenital malformations is a query tool for anyone interested or working in the field of birth defects. The atlas can be used by individuals coding medical diagnosis into an ICD-10 system, health workers wanting to improve diagnostic accuracy, or the general community wishing to learn more about specific birth defects. It is available in English, Portuguese and Spanish: [www.atlaseclamc.org](http://www.atlaseclamc.org).

Since the release of version 2.0 of the ECLAMC Atlas on 20 May 2013 the site has received 98,155 visits by 87,686 users; 11% of the users have returned to the page on more than one occasion. Over 16 months, the average daily visits has been increasing, reaching more than 270 daily visits in the past 3 months. The most frequent used language is Portuguese with 30%, followed by English in the US with 19%, and Spanish outside Spain with 19%. The Atlas has had visits from users in 180 countries worldwide.

### News from the Headquarters and Executive Committee

The publication of the Quarterly Reports has been restarted. The reports from 3rd quarter 2011 to 2nd quarter 2013 are available into the member area of the ICBDSR website, since the quarterly data provided for QR are provisional. You can find also a table that summarizes the increases observed in the most recent quarters.

### Upcoming deadlines

- **October 15:** feedback on the 41<sup>st</sup> Annual Meeting (Survey Monkey evaluation form – only for attendees)
- **November 20 :** data for the 4<sup>th</sup> Quarter 2013
- **November 30:** annual data (2012, or the most recent available year), to be published in the Annual Report 2014
- **December 31:** last call for payment of 2014 annual dues from missing programs (this can affect the voting right)

***Would you like to contribute with any news from your program for next Monthly Newsletter?***

*Please send contributions, comments or questions to [centre@icbdsr.org](mailto:centre@icbdsr.org)*