



Press release

ISCIDD, the first international society of cancer in people with intellectual and developmental disabilities was founded on February 7<sup>th</sup> 2014 in Montpellier, France, at the end of the first international symposium on the subject, co-organized by Oncodefi association ([www.oncodefi.org](http://www.oncodefi.org)) and the Cancéropôle Grand Sud-Ouest ([www.canceropole-gso.org](http://www.canceropole-gso.org)).

ISCIDD is based on the Montpellier Declaration which says:

French

**1° Les personnes avec déficience intellectuelle doivent avoir un égal accès aux services de santé en oncologie: la prévention, le dépistage, le traitement, l'accompagnement et les soins palliatifs, conformément à ceux disponibles pour la population générale.**

*Cette déclaration est en accord avec la Convention internationale des Nations Unies sur les Droits des Personnes Handicapées de 2006.*

**2° L'ISCIDD ambitionne de mieux comprendre et d'approfondir les connaissances spécifiques dans le domaine du cancer chez les personnes avec déficiences intellectuelles par la recherche fondamentale et appliquée, la collaboration, le partage d'expertise et des connaissances avec d'autres chercheurs et cliniciens, avec les familles et avec les personnes déficientes intellectuelles. Nous sommes convaincus que les progrès dans ce domaine seront également profitables à l'ensemble de la population.**

English

**1° People with intellectual disabilities should have equal access to health service provision in cancer: preventative measures, screening, curative and palliative treatment and care, in line with those available to the general population. This is in accordance with the 2006 UN Convention on the Rights of People with Disabilities.**

**2° A society was founded in Montpellier: International Society on Cancer and Intellectual and Developmental Disabilities (ISCIDD).**

**ISCIDD aims to understand and address the specific features of cancer and people with intellectual and developmental disabilities, through fundamental and applied research, collaboration and sharing expertise and knowledge with other researchers, clinicians, with families and with disabled people. We are convinced that progress in this field will also be of benefit to the general population.**

The society opens unexpected and promising new horizons. It was founded in response to the observation that people with intellectual disability who are born with mental retardation or who acquired this impairment during childhood and adolescents develop as many cancers as people in the general population. However, in many respects these cancers are different from those in the general population, often not well known and difficult to treat. Furthermore, it has been noted that there are inequalities in access to cancer services, and particular difficulties around providing support for people with intellectual disabilities who have cancer, their families and carers.

New horizons are opening around genetic links that have been recently discovered between cancer and intellectual disability. These links and the observation that some genetic conditions associated with intellectual disability protect against cancer challenge some current concepts. There are no fewer than 2,000 conditions associated with intellectual disability. There are as many new research avenues for intellectual disability and cancer. There are also new possibilities for international collaboration on the development of screening practice, easy-read information materials, general cancer care and palliative care.

The ISCIDD aim is to gather very various competences on the matter of care, support, cancer treatment, psychology, sociology, cancer biology, genetics and molecular biology in order to improve quality of care for persons with intellectual disability, and to promote cancer understanding and treatment. It is a huge task. However, the Montpellier symposium has already led to cooperative projects between teams, demonstrating that the process has begun.

Members of the ISCIDD will attend a second symposium in 2016, in another great European town.

Professor Jean-Bernard Dubois  
Oncodefi President

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