



Country Report-Japan

Hiroshi Tamai, MD. PhD,
President of Japan Down Syndrome Society (JDS)

Hiroko kondo

Director of Japan Down Syndrome Society







Topic 1

Translation of Guideline for adults with Down syndrome of Global Down Syndrome Foundation

We have almost finished the translation of the Guideline for adults with Down syndrome of the Global Down Syndrome Foundation. It will be open on the website of Global DSF and Japan Down Syndrome Association.

It will be helpful for not only medical doctors but parents and caregivers in Japan.





Expression of JDS's opinion for NIPT (Non-invasive Prenatal Genetic Testing)

- 'JDS has repeatedly expressed its concern about NIPT to the expert committee of Government. There are worries about using mass screening, while we are not against the personal judgment of acceptance of NIPT.
- There will be about 300 authorized hospitals where NIPT is implemented.





Rapid regression in the adolescent and early adulthood

- We have to clarify the clinical diagnosis for the rapid regression in the adolescent. They are perplexed and isolate themselves from society.
- Anxiety and stress were observed before the start of strong preferences or inflexibility.
- We conduct a seminar for the supporter.





Topic 4–1

Pediatric to Adult Care

- The complications in childhood are well known to pediatricians, but a different type of complications are detected in adults with DS, for example, aging and the Alzheimer's dementia.
- Physicians for adults are more appropriate rather than pediatricians for dementia and other adult-onset diseases.
- •Therefore, transitioning from pediatricians to physicians for adult care in adolescence is very important.





Topic 4–2

Pediatric to Adult Care

- Transition Readiness
 - 1) Assessment for youth with DS
- 2) Assessment for parents and caregivers of the person with DS
- 3) Medical summary for young adults with DS
- 4) Self-care assessment