

# Assessment of Down syndrome-associated Arthritis: A Survey of Down syndrome Clinic Providers

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## BACKGROUND

- Inflammatory arthritis in children with Down syndrome (DS) was first described in 1984 and is now termed DS-associated arthritis (DA)
- Studies have shown there is an average 19-month delay in diagnosis
- Most patients present with polyarticular (> 5 affected joints) rheumatoid factor and anti-nuclear antibody (ANA) negative disease
- There is no standardized approach to assessment of DA

## OBJECTIVES/AIMS

- To describe provider perspectives toward diagnostic approach and assessment for DA
- To provide baseline information upon which to design future studies.

## DESIGN/METHODS

- An electronic survey, organized into sections regarding individual practices of diagnostic approach and assessment of DA, was sent to the Down Syndrome Medical Interest Group electronic list-serv.
- Survey responses were voluntary
- Results were analyzed by descriptive statistics.

## RESULTS

- 39 respondents from DSMIG list-serve
- Most respondents were physicians (74%) and specialized in pediatrics (33%)
- Most had > 10 years since completing training (68%), > 75% clinical time (49%), and worked in an academic setting (64%).
- The majority (77%) of providers knew patients with DS were at risk for inflammatory arthritis and 75% take measures to screen for arthritis

Respondent Characteristics	Respondents (n = 39)
<b>How Do You Diagnose DA</b>	<b>Affirmative Responses, n (%)</b>
History	32(82)
Physical exam	28(72)
Laboratory tests	1(3)
Imaging	1(3)
<b>What laboratory Tests are Used for Diagnosis</b>	<b>Affirmative Responses, n (%)</b>
Complete blood count	21 (54)
C-reactive protein	26(67)
Sedimentation rate	25(64)
Anti-nuclear antibody	22(56)
Rheumatoid factor	19(49)
Human leukocyte antigen B27	3 (8)
Uric Acid	4 (10)
Complement level	4 (10)
Immunoglobulin levels	2 (5)
Lactate dehydrogenase	3(8)
<b>What laboratory Tests are Used for Diagnosis</b>	<b>Affirmative Responses, n (%)</b>
X-ray	16 (41)
Computerized tomography scan	22 (56)
Ultrasound	8 (21)
Magnetic resonance imaging	1 (3)
<b>Do you Educate Families about DA</b>	<b>Affirmative Responses, n (%)</b>
Yes	19 (49)

## CONCLUSIONS

- This is the first study to evaluate provider perspectives towards diagnostic approach and assessment of DA
- Most Down syndrome clinic providers are aware of DA, but education to families about the risk for DA is lacking.
- Most utilize history and physical exam, to assess for DA
- Laboratory tests and imaging modalities are not ordered frequently to assess for DA.
- More research is needed to determine optimal education of families, diagnostic approach, assessment specific to DA and optimal education to families.

No Relevant disclosure from the authors.

