



ORAL PRESENTATION

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The childhood arthritis & rheumatology research alliance network registry: demographics and characteristics of the initial 6-month cohort

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Purpose

In 2009, the Childhood Arthritis and Rheumatology Research Alliance (CARRA) established a longitudinal multi-center, multiple disease U.S. national registry (CARRAnet) for pediatric rheumatology with the intent of providing 60 participating clinical sites a new framework to drive observational clinical research and evidence-based care. CARRAnet seeks to enroll up to 20,000 subjects with childhood-onset rheumatic disease and twice yearly follow-up. We report baseline characteristics of the initial 6-month enrollment cohort; disease-specific results are reported separately.

Methods

Enrollment commenced 5/29/2010 with data available through 12/28/10. Inclusion criteria comprised 1 of 8 categories of defined rheumatic disease with onset before the 16th birthday in subjects ≤ 21 years (localized scleroderma, juvenile dermatomyositis, juvenile idiopathic arthritis, juvenile primary fibromyalgia syndrome, SLE or mixed connective tissue disease, sarcoidosis, systemic sclerosis, and vasculitis). A common baseline data set and 1 disease-specific data set was completed on each participant by interview and chart review. Data cleaning and analysis employed Microsoft Excel and Access (Microsoft Corp), SAS (SAS Institute), and R (R Foundation for Statistical Computing).

Results

1638 subjects were enrolled from 27 centers throughout the US. The analysis cohort reflected 1371 subjects,

Table 1 Summary characteristics of CARRAnet initial cohort

Demographic measures	N (%)
Total participants studied	1371
Female gender	1024 (75%)
White/caucasian	1187 (87%)
Age at onset of symptoms, mean in years	7.2
Age at baseline visit, mean in years	11.8
Black or African American	127 (9%)
Asian	45 (3%)
American Indian or Alaska Native	30 (2%)
Native Hawaiian or Pacific Islander	9 (<1%)
Hispanic ethnicity	150 (11%)
Primary rheumatic diagnosis	
Juvenile idiopathic arthritis	1051 (77%)
Juvenile dermatomyositis	109 (8%)
Systemic lupus erythematosus	100 (7%)
Localized scleroderma	43 (3%)
Mixed connective tissue disease	23 (2%)
Vasculitis	23 (2%)
Systemic sclerosis	9 (<1%)
Sarcoidosis	8 (<1%)
Juvenile primary fibromyalgia syndrome	6 (<1%)
Growth parameters	
Weight Z-score	Mean & (Range) 0.28 (-5.3 – 4.7)
Height Z-score	-0.14 (-19.7 – 9.4)
BMI Z-score	0.38 (-5.0 – 4.1)
Assessments (scale: best -> worst)	
Physician global assess disease activity (0 – 10)	Mean & (Range) 1.6 (0 – 10)
Subject global assess disease activity (0 – 10)	2.3 (0 – 10)
Subject pain score (0 – 10)	2.4 (0 – 10)
CHAQ (0 – 3)	0.33 (0 – 3)
HRQOL – Good, very good, excellent (%)	96%

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Table 1 Summary characteristics of CARRAnet initial cohort (Continued)

HRQOL – Very poor, poor (%)	3%
Family history (first degree relative) of	N (%)
Psoriasis	82 (6%)
Rheumatoid arthritis	71 (5%)
Autoimmune thyroiditis	62 (5%)
Fibromyalgia	61 (4%)
Juvenile idiopathic arthritis	55 (4%)
Diabetes type I	35 (3%)
Inflammatory bowel disease	31 (2%)
Systemic lupus erthematosus	28 (2%)
Spondyloarthritis or ankyl. spondylitis	16 (1%)
Multiple sclerosis	13 (1%)
Celiac disease	10 (1%)
Uveitis	5 (<1%)
Medication use	N (%)
Steroids (ever)	1010 (74%)
Steroids (longterm daily, ever)	644 (47%)
Steroids (IV pulse, ever)	212 (15%)
Steroids (IA, ever)	529 (39%)
Biologics (ever)	560 (41%)
Biologics (current)	429 (31%)
TNF- α Blockers (current)	338 (25%)
DMARDs (ever)	1107 (81%)
DMARDs (current)	1021 (75%)
Methotrexate (current)	620 (45%)
NSAIDs (current)	625 (46%)
Opioids (current)	17 (1%)

predominantly JIA; 63 variables were collected for the shared baseline form with summary statistics presented in the figures. The population reported overall good to excellent health by patient and physician report: 96% with mean HRQOL good to excellent; physician mean global assessment of disease activity (PGAS) 1.6 (0-10 scale). PGAS correlated with subject reports (CHAQ, subject global, subject pain scores – Pearson corr 0.33, 0.39, 0.42 respectively). Medication use was prevalent, including 74% ever on steroids, 41% ever on biologics, and 31% currently on biologics. Growth was within normal on average, but exhibited wide deviation ($-5.3 > \text{weight } Z > 4.7$, $-19.7 > \text{height } Z > 9.4$). A similarly wide range was seen on both objective and subjective measures, identifying probable subpopulations with high disease activities.

Conclusion

The initial CARRAnet cohort reflects predominantly low disease activity with favorable self-reports. This is not a population study and issues of enrollment bias require further investigation. Despite the overall well-being of

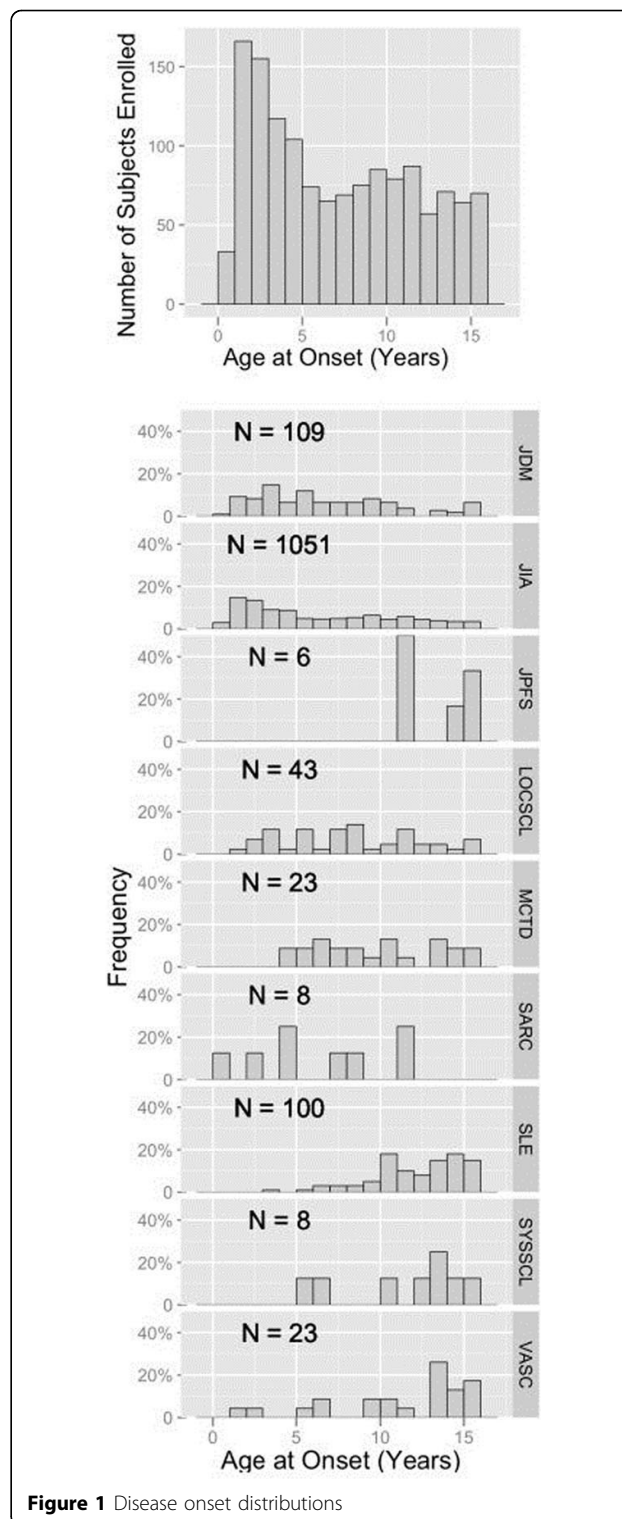


Figure 1 Disease onset distributions

the population, the high use of steroids, biologics, and DMARDs, along with significant subpopulations concerning for high disease activity, are important areas of future focus.

Disclosure

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