



INITIAL RESULTS FROM THE CASCADE-FH REGISTRY: CASCADE SCREENING FOR AWARENESS AND DETECTION OF FAMILIAL HYPERCHOLESTEROLEMIA

Poster Contributions

Poster Hall B1

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Background: Familial Hypercholesterolemia (FH) is a genetic disorder that leads to substantially elevated levels of low-density lipoprotein cholesterol (LDL-C). The 2013 ACC/AHA lipid guidelines denote an LDL-C level ≥ 190 mg/dL (suggestive of FH) as an independent high-risk feature. While it is estimated that over 600,000 individuals in the U.S. have FH, fewer than 10% of these have been formally diagnosed.

Methods: As the only active FH registry in the US, the CASCADE-FH Registry, an initiative of the FH Foundation (FHF), utilizes a novel, dual-pathway enrollment design: 1) Enrollment of formally diagnosed FH patients by a clinical provider, with abstraction of clinical data from medical records; 2) Self-enrollment and data entry via an online portal for participants meeting LDL criteria consistent with FH. Followup data will be captured annually.

Results: A total of 1,236 FH patients have been enrolled (165 from the online portal and 1,071 from 11 specialty sites). The median pretreatment LDL-C (IQR) was 249 mg/dL (211-310 mg/dL). Just over half were treated with high-intensity statins. LDL apheresis is currently being used in 7.2% of patients. Updated data from additional patients and longitudinal follow-up data will be available for presentation at the ACC sessions in March 2015.

Conclusion: The CASCADE-FH Registry is a unique partnership between FH patients, the FH Foundation and clinical researchers to raise awareness of the need for improved diagnosis and treatment of FH in contemporary practice.

Table. Baseline Characteristics of the CASCADE FH Patient Population (September 2013 – September 2014).

Variable	Overall (N=1236)	Online Portal (N=165; 13.3%)	Clinical Sites (N=1071; 86.7%)
Median age, years	53	52	53
(IQR)	(37, 64)	(41, 60)	(36, 65)
White race, %	81.4	92.7	79.6
Female sex, %	58.7	72.7	56.6
Formal FH diagnosis, %	97.4	80.6	100.0
Family member with FH, %	31.5	46.7	29.2
Prior MI, %	12.4	17.2	11.6
Prior PCI, %	17.0	19.4	16.6
Prior CABG, %	13.8	14.9	13.6
Historical Highest LDL-C (mg/dL)	249 (211-310)	290 (231-355)	245 (210-303)
Current LDL-C (mg/dL)	143 (107-196)	150 (118-200)	143 (107-196)
Currently treated with statins, %	74.5	72.7	76.1
Currently treated with high- intensity statins*, %	54.8	63.2	53.5

Abbreviations: MI=myocardial infarction; PCI=percutaneous coronary intervention; CABG=coronary artery bypass graft

*High-intensity statins defined as atorvastatin ≥ 40 mg or rosuvastatin ≥ 20 mg

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