

SETTING THE COMMUNICATION BAR FOR AN ORPHAN DISEASE

The Impact of a Coordinated Secondary Publications Plan on Educating Clinicians

HIGHLIGHTS Publications Plan

TARGET AUDIENCES

HAE patients present in a host of locations. A large number of specialty and subspecialty clinicians needed to be engaged. In total, 16 separate audiences were reached.

PREACHING TO THE CHOIR

Only allergist / immunologist typically recognized HAE. They would require updated data from time to time, but in general, they knew HAE very well.

CHANGING PERSPECTIVES

Researching the potential target audiences it became clear that for groups such as Emergency Medicine, it would be essential to change their baseline perspective in order to impart any change.

CONTINUING EFFORTS

Many lessons were learned as a result of the HAE publications plan. Chief amongst these was that continued efforts would be necessary in order to bring about true recognition for HAE patients.



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A supplement to the Journal of the American Academy of Physician Assistants
APRIL 2018

Introduction: An Overview of Hereditary Angioedema and the Role of the Physician Assistant
Kramer L. Bushart, PhD, PA-C

Diagnosis and Treatment of Hereditary Angioedema in the Primary Care Setting: A Review for Physician Assistants
Kramer L. Bushart, PhD, PA-C

Laryngeal Presentation of HAE in the Emergency Department Setting
Mey L. Howell, MS, PA-C

HAE: The Gastroenterology



Diagnosis and management of angioedema with abdominal involvement: A gastroenterology perspective

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Received: May 2, 2018; Revised: June 18, 2018; Accepted: June 18, 2018

World J Gastroenterol 2018; 22(16): 4723-4730
ISSN 1007-9327 (print)
ISSN 1007-9327 (online)
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INTRODUCTION

BMC Blood Disorders 2018, 18:1
<http://www.biomedcentral.com/10.1186/s12916-018-0121-1>



Hereditary angioedema: New therapeutic options for a potentially deadly disorder

Frank J. Edelman

Abstract
Although the biochemistry of hereditary angioedema (HAE) is fairly well understood today, the lag in diagnosis of a disease or illness suggests that clinicians have low awareness of this disease. This lag in diagnosis and better treatment certainly stems from the rarity and complexity of the presentation which can be easily mistaken for allergic and idiopathic reactions alike. The symptoms of the disease include acute swelling of any or multiple parts of the body. The attacks may be frequent or rare, and they may only occasionally severely disrupts normal or personal functioning in mild cases and symptoms which start to abdominal fullness or erythema on the most severe cases. Given that these patients are at significant risk for poor quality of life and death, greater awareness of this disease is needed to ensure that newly available, effective medications are used in these patients. These new medications represent significant advances in HAE therapy that need to be recognized at the primary care level and in the subspecialty of this disease. The clinical presentation of HAE, overlapping symptoms with angioedema, and available therapeutic interventions.

Introduction

No medications are available for prophylaxis and

ViroPharma was developing a treatment for an orphan disease known as Hereditary Angioedema (HAE). The development timeline for the therapy had ViroPharma reaching the US market 18-24 months ahead of several potential competing products. Having the initial therapy coming to market required ViroPharma to establish the communication foundation for the disease. ISC was engaged to assist ViroPharma in identifying the proper target specialty and subspecialty segments, and to develop and execute a publication plan to reach those segments in a timely fashion.

Problem Statement: Being the first to market in a new therapeutic segment is associated with many advantages and also a number of disadvantages. In the case of ViroPharma, although they would reap financial benefit of reaching the market first with their HAE treatment, they also were obliged to complete the foundational education efforts for that market segment.

ISC's Solution: ISC was engaged to evaluating the potential points of treatment for HAE patients within the broader healthcare system. From there, ISC established a secondary publication plan to reach the clinicians involved at the various treatment points. In the end, this amounted to a total of 16 different professional audiences.

Implementation: ISC medical writers and editors supported the authors on each paper in an effort to ensure the timely development, submission, and eventual publication of the audience-specific manuscripts. Some of the papers had single authors, while others had as many as six. The lead author for each paper was a specialist in the audience being addressed.

Continual communication with key stakeholders during large-scale publication plans is essential. ISC routinely updated the client on the status of the effort, as well as the authors of the respective manuscripts.

The Final Product: The crowning element to the Publication Plan was a supplement to the Journal of the American Academy of Physician Assistants (JAAPA). The five-part supplement was developed in only 16 weeks. The publication of the supplement occurred three weeks prior to the annual national meeting of the AAPA.

The secondary publication plan established for ViroPharma included the following key results:

- 02 – years the plan took to execute
- 03 – phases that made up the plan
- 04 – months to publish supplement
- 16 – separate audiences reached
- 21 – months to execute full program
- 24 – manuscripts made up the plan
- 33 – number of authors involved
- 69 – percent published in year submitted
- 73 – percent accepted by initial journal

As a result of the extensive efforts made on the secondary publications program, ViroPharma was well positioned within the HAE segment in the eyes of a wide variety of clinicians.

Publication PLANNING