



Report of the Inhibitor Committee (2014)

Membership

Manuel Carcao (Chair as of May, 2013)
Jerry Teitel (Past chair)
Alfonso Iorio
David Lillicrap
Georges Rivard
Jean St-Louis
Paul Moorhead (joined in 2013)
Natalia Rydz (joined in 2013)
Irwin Walker (stepped down in 2013)

This past year witnessed a number of changes in the membership of the Inhibitor Subcommittee.

- 1) Manuel took over as chair from Jerry who over the past 7 years has led the Subcommittee.
- 2) Irwin after many years of dedicated service stepped down from the Subcommittee. The Inhibitor Subcommittee thanked Irwin for his tremendous contributions.
- 3) Paul and Natalia were invited to join the Subcommittee based on their interest/past experience in this area of research. They also provide broader regional representation to the subcommittee.

Meetings

The members met formally twice during this past year (once in Amsterdam in conjunction with the ISTH meeting and once in New Orleans in conjunction with the ASH meeting). They discussed a number of initiatives (see below):

Initiatives that the Inhibitor Subcommittee is planning

- 1) Undertake a **survey of the current status of inhibitor patients in Canada**. This would be to determine how many patients with inhibitors there are, where are they, how are they being managed, are they on ITI and if so what regimen. A big focus of this review would be to look at the **status of the long-term inhibitor patient**. These are mainly adults who have had inhibitors for most of their lives.
- 2) **Updating the Guide to the Management of Patients with Inhibitors**. This was previously done (4 years ago) with some sponsorship from Baxter. The booklet was published in 2010.
- 3) The Inhibitor committee is considering developing a **Canadian Standard ITI regimen** which would likely include some type of algorithm for the management of inhibitor patients. The goal of this would be to have a standard consensus driven approach to:
 - a. when to start ITI
 - b. what regimen to use
 - c. how to monitor patients on ITI and when to consider success or failure of ITI
 - d. the protocol would **NOT** specify the type of factor to be used for ITI

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4) The inhibitor subcommittee is considering undertaking a **prospective study on patients who develop inhibitors**. This prospective study would also include following them through ITI.

All of these initiatives will require the commitment of the entire AHCDC to be successful and as such will be presented and briefly discussed at the upcoming AHCDC meeting in Montreal.

Respectfully submitted,

Manuel Carcao (on behalf of the Inhibitor Subcommittee)
March 25, 2014