

The Kidney Foundation of Canada – Clinical Trial Communication Guidelines

The Kidney Foundation of Canada will provide information about clinical trials, according to the following principles. Please note that the sharing of market research is not approved within this policy and is not supported by The Kidney Foundation of Canada sharing guidelines.

NOTE: Please note that within the context of the following document, the term "sponsor" is defined as the individual, institution, company or organization that takes the responsibility to manage or finance a clinical trial but who does not conduct or oversee the clinical trial directly. The term "sponsor-investigator" is defined as the individual, institution, company or organization that takes responsibility as the sponsor, but who also conducts or oversees the trial directly. These terms do not denote or classify any relationship directly with The Kidney Foundation of Canada.

- 1. The Kidney Foundation of Canada believes that all patients and their families should have timely, accurate information about ongoing clinical trials that may be relevant to their healthcare situation. Knowledge about current trials may assist patients and their families in making informed decisions and may empower them to discuss options with their healthcare provider. The Kidney Foundation of Canada does not aim to influence healthcare decisions; and information is provided for education and awareness only and will be noted as such in Foundation webpages and communiques. Questions about trials must be addressed by the individual's healthcare team.
- 2. The Kidney Foundation of Canada will disseminate clinical trial information in a fair and balanced and factual manner based on information provided by the sponsor or sponsor-investigator or their representative. Additional commentary, assumption, or information will not be added, and no information will be utilized to attempt to sway or influence one's decision to participate or investigate any ongoing trial.
- 3. The Kidney Foundation of Canada may share with the sponsor or sponsor-investigator any community-wide observations and insight regarding the current state of care, including feedback on perceived barriers or challenges to patient recruitment or participation in trials. This may include feedback on proposed trial design, recruitment or implementation strategies. This information is provided as community-wide feedback, and no individual commentary or information will be utilized.

- 4. The Kidney Foundation of Canada will only provide information about clinical trails that have been approved by appropriate regulatory bodies, and that have all appropriate ethical considerations in place. Connection to clinicaltrials.gov links will be required for all trials wishing to be shared via Kidney Foundation of Canada mechanisms.
- 5. The Kidney Foundation of Canada does not communicate information that could be interpreted as favouring, advertising, or promoting a specific drug or treatment, or that could be construed as favouring a specific sponsor, sponsor-investigator or institution. To ensure fair representation of active trials in Canada, all trials that meet the required ethical and relevance criteria will be shared through our channels without bias. Dissemination of ongoing trials is independent of any other additional relationship or interaction that may exist between The Kidney Foundation of Canada and the trial sponsor, sponsor-investigator or host institution.
- 6. Standardized templates requesting specific trial information will be provided to trial sponsors or sponsor-investigators to create informative and accurate content. The Kidney Foundation of Canada retains the right to suggest modifications including suggested wording and/or formatting and will work with the sponsor or sponsor-investigator to ensure that all communications are in line with both The Kidney Foundation of Canada best practice, and in alignment with ethical requirements of each individual study.
- 7. The Kidney Foundation of Canada may share clinical trials through our website, social media channels and newsletters. Due to volume of potential trials, The Kidney Foundation of Canada cannot promise direct attention to the activation of each new study but will ensure that traffic is continuously driven to the clinical trials page through standard dissemination.
- 8. All sharing of Clinical trial information is mediated through the National office research and communications departments. Information on newly activated studies will be provided to our branches, but no guarantees can be made about branch uptake or independent communication of trial information. Clinical trials may NOT be advertised directly through other Kidney Foundation of Canada communication channels without the approval of the Research department.
- 9. Kidney Foundation staff, volunteers, board members and consultants have a responsibility to represent The Kidney Foundation of Canada in their conduct. Information about treatment options or trials that is shared in a way that is accessible to the community via social media (including blogs, etc.) must adhere to the guidelines put forth in this document. Advertisement of any non-approved treatment options or trials is not allowed.