

# Resources to Assist in the Building of a Patient Group

It can be difficult for small or early stage organizations to easily locate resources that provide an outline of the basic steps to follow when getting started. In 2017, CORD assembled a group of its members to ask them what tools they needed to build and better manage their organizations, ultimately leading to the development of a series of themes. Building upon this, CORD used Charity Village's Knowledge Centre to identify a number of web-based training tools and guides to meet these needs.

This list of resources is a collection of free tools from Canada's largest non-profit on-line community. CORD will endeavor to maintain the collection to remain current and adapt its content to the evolving needs of its members. Input is welcome! Let us know how we can further improve this inventory to best meet the needs of Canada's rare disorder community.

Charity Village Knowledge Centre Resources

<https://charityvillage.com/cms/knowledge-centre>

A new Overview Resource: *The small non-profit podcast*

<https://charityvillage.com/cms/knowledge-centre/the-small-nonprofit-podcast>

*"The Small Nonprofit podcast, by CharityVillage and The Good Partnership, gives you down-to-earth, practical and actionable expert guidance on how to run a small nonprofit."*

## Themes and Resources

Item	Description/steps	Charity Village Section	Charity Village Courses	Web Site Address
Identify Founding Leadership	Who are the founders?	Management	Inspiring Leadership: A six-part series	<a href="https://charityvillage.com/cms/content/topic/inspiring_leadership_a_crucial_competency#.W7zqNC8ZP-Y">https://charityvillage.com/cms/content/topic/inspiring_leadership_a_crucial_competency#.W7zqNC8ZP-Y</a>
			Best Board member orientation	<a href="https://charityvillage.com/cms/content/topic/the_best_board_member_orientation_how_to_set_your_new_directors_immediately_up_for_success/last/228#.W7zx2S8ZP-Y">https://charityvillage.com/cms/content/topic/the_best_board_member_orientation_how_to_set_your_new_directors_immediately_up_for_success/last/228#.W7zx2S8ZP-Y</a>
	What specific competencies are required to shape the organization and launch the project?		Top Canadian Charity Law Compliance Issues	<a href="https://charityvillage.com/cms/content/topic/top_canadian_charity_law_compliance_issues_for_canadian_registered_charities/last/228#.W7zyFi8ZP-Y">https://charityvillage.com/cms/content/topic/top_canadian_charity_law_compliance_issues_for_canadian_registered_charities/last/228#.W7zyFi8ZP-Y</a>
			Tools for non-profit leaders: Essential governance tools	<a href="https://charityvillage.com/cms/content/topic/tools_for_nonprofit_leaders_essential_governance_tools/last/228#.W7zzri8ZP-Y">https://charityvillage.com/cms/content/topic/tools_for_nonprofit_leaders_essential_governance_tools/last/228#.W7zzri8ZP-Y</a>
			Overcoming Founder's Syndrome: Practical tips for founders, boards of directors and employees	<a href="https://charityvillage.com/cms/content/topic/overcoming_founder_s_syndrome_practical_tips_for_founders_boards_of_directors_and_employees/last/225#.W7zxYi8ZP-Y">https://charityvillage.com/cms/content/topic/overcoming_founder_s_syndrome_practical_tips_for_founders_boards_of_directors_and_employees/last/225#.W7zxYi8ZP-Y</a>
	Establish governance	Volunteer Engagement	Volunteer and staff roles and responsibilities	<a href="https://charityvillage.com/cms/content/topic/volunteer_and_staff_roles_and_responsibilities/last/145#.W7z-ES8ZP-Y">https://charityvillage.com/cms/content/topic/volunteer_and_staff_roles_and_responsibilities/last/145#.W7z-ES8ZP-Y</a>
	What are the long-term goals, or desired future state (Vision)?	Management	Building a new not-for-profit organization	<a href="https://charityvillage.com/cms/content/topic/building_a_new_not_for_profit_organization_/last/235#.W70F_y8ZPow">https://charityvillage.com/cms/content/topic/building_a_new_not_for_profit_organization_/last/235#.W70F_y8ZPow</a>  <a href="https://charityvillage.com/cms/content/topic/in_the_beginning_things_to_consider_before_starting_your_nonprofit_venture/last/235#.W70Gri8ZPow">https://charityvillage.com/cms/content/topic/in_the_beginning_things_to_consider_before_starting_your_nonprofit_venture/last/235#.W70Gri8ZPow</a>

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Vision and Mission	<b>Mission</b> Why does the organization exist?		Goals to save the world: How to prioritize and set strong, realistic sustainability goals	<a href="https://charityvillage.com/cms/content/topic/goals_to_save_the_world_how_to_prioritize_and_set_strong_realistic_sustainability_goals/last/233#.W70IbC8ZPow">https://charityvillage.com/cms/content/topic/goals_to_save_the_world_how_to_prioritize_and_set_strong_realistic_sustainability_goals/last/233#.W70IbC8ZPow</a>
	What does the organization seek to accomplish?			
	How will the organization accomplish its goals?		Four keys to financial success in small to mid-size non-profits and charities	<a href="https://charityvillage.com/cms/content/topic/recorded_webinar_four_keys_to_financial_success_in_small_to_mid_size_nonprofits_charities/last/239#.W70KDy8ZPow">https://charityvillage.com/cms/content/topic/recorded_webinar_four_keys_to_financial_success_in_small_to_mid_size_nonprofits_charities/last/239#.W70KDy8ZPow</a>
	What will be the legal status of the organization?		Reading and Understanding Financial Statements	<a href="https://charityvillage.com/cms/content/topic/i_m_passionate_about_the_cause_do_i_really_need_to_learn_to_read_and_understand_financial_statements_and_reports/last/225#.W7ztEy8ZP-Y">https://charityvillage.com/cms/content/topic/i_m_passionate_about_the_cause_do_i_really_need_to_learn_to_read_and_understand_financial_statements_and_reports/last/225#.W7ztEy8ZP-Y</a>
	Tax Status?		Beyond the premiums: Understanding non-profit insurance	<a href="https://charityvillage.com/cms/content/topic/beyond_the_premiums_understanding_nonprofit_insurance/last/225#.W7z26C8ZP-Y">https://charityvillage.com/cms/content/topic/beyond_the_premiums_understanding_nonprofit_insurance/last/225#.W7z26C8ZP-Y</a>
Strategic Planning	Operationalize the Mission of the Organization	Management	What is a strategic plan?	<a href="https://charityvillage.com/cms/content/topic/what_is_a_strategic_plan_/last/238#.W70A8C8ZP-Y">https://charityvillage.com/cms/content/topic/what_is_a_strategic_plan_/last/238#.W70A8C8ZP-Y</a>
	Create a Work Plan		Best practices in strategic planning	<a href="https://charityvillage.com/cms/content/topic/best_practices_in_strategic_planning/last/238#.W7z_Cy8ZP-Y">https://charityvillage.com/cms/content/topic/best_practices_in_strategic_planning/last/238#.W7z_Cy8ZP-Y</a>
	Establish Accountability		Translating vision into action	<a href="https://charityvillage.com/cms/content/topic/translating_vision_into_action/last/238#.W7z_KC8ZP-Y">https://charityvillage.com/cms/content/topic/translating_vision_into_action/last/238#.W7z_KC8ZP-Y</a>
	Identify Resource Needs		Balanced Scorecard: From strategic plan to effective execution	<a href="https://charityvillage.com/cms/content/topic/the_balanced_scorecard_from_strategic_plan_to_effective_execution/last/225#.W7z2cy8ZP-Y">https://charityvillage.com/cms/content/topic/the_balanced_scorecard_from_strategic_plan_to_effective_execution/last/225#.W7z2cy8ZP-Y</a>

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Create a Presence  Outreach  Recruitment	Create a visual identity to become recognizable	Management	Trademarks and the voluntary sector in Canada: the 5 W's	<a href="https://charityvillage.com/cms/content/topic/trademarks_and_the_voluntary_sector_in_canada_the_5_ws/last/239#.W70Mai8ZOCQ">https://charityvillage.com/cms/content/topic/trademarks_and_the_voluntary_sector_in_canada_the_5_ws/last/239#.W70Mai8ZOCQ</a>
	Build or share web-based resources		Upgrade your website usability	<a href="https://charityvillage.com/cms/content/topic/upgrade_your_website_s_usability_enhance_your_bottom_line_3_ways_a_great_online_user_experience_can_/last/239#.W70Lry8ZOCQ">https://charityvillage.com/cms/content/topic/upgrade_your_website_s_usability_enhance_your_bottom_line_3_ways_a_great_online_user_experience_can_/last/239#.W70Lry8ZOCQ</a>
	Begin early outreach using social media	Communications – Marketing	How Canadian organizations are using Facebook for engagement and advocacy	<a href="https://charityvillage.com/cms/content/topic/how_canadian_organizations_are_using_facebook_for_engagement_and_advocacy/last/142#.W70NOC8ZOCQ">https://charityvillage.com/cms/content/topic/how_canadian_organizations_are_using_facebook_for_engagement_and_advocacy/last/142#.W70NOC8ZOCQ</a>
	Using existing channels to build a network, e.g. CORD, Orphanet, Rare Disease Foundation, similar groups		Beyond the buzzwords: Social and mobile strategies (recorded webinar)	<a href="https://charityvillage.com/cms/content/topic/beyond_the_buzzwords_social_and_mobile_strategies_recorded_webinar/last/142#.W70PYS8ZOCQ">https://charityvillage.com/cms/content/topic/beyond_the_buzzwords_social_and_mobile_strategies_recorded_webinar/last/142#.W70PYS8ZOCQ</a>
	Build membership	Communications – Public Engagement	Isn't it time for a new story? Innovative approaches to nonprofit storytelling	<a href="https://charityvillage.com/cms/content/topic/isn_t_it_time_for_a_new_story_innovative_approaches_to_nonprofit_storytelling/last/142#.W70Ply8ZOCQ">https://charityvillage.com/cms/content/topic/isn_t_it_time_for_a_new_story_innovative_approaches_to_nonprofit_storytelling/last/142#.W70Ply8ZOCQ</a>
			22 high impact, low cost social media opportunities for nonprofits	<a href="https://charityvillage.com/cms/content/topic/22_high_impact_low_cost_social_media_opportunities_for_nonprofits/last/142#.W70P2S8ZOCQ">https://charityvillage.com/cms/content/topic/22_high_impact_low_cost_social_media_opportunities_for_nonprofits/last/142#.W70P2S8ZOCQ</a>
Build Advocacy	Craft a Communications Strategy	Communications – Public Engagement	Media relations for nonprofits: A primer, reading list and advice from the pros	<a href="https://charityvillage.com/cms/content/topic/media_relations_for_nonprofits_a_primer_reading_list_and_advice_from_the_pros/last/142#.W70QGi8ZOCQ">https://charityvillage.com/cms/content/topic/media_relations_for_nonprofits_a_primer_reading_list_and_advice_from_the_pros/last/142#.W70QGi8ZOCQ</a>
	Learn how to talk to Government and Businesses		Five tips on becoming a media star	<a href="https://charityvillage.com/cms/content/topic/five_tips_on_becoming_a_media_star/last/232#.W70DLi8ZPow">https://charityvillage.com/cms/content/topic/five_tips_on_becoming_a_media_star/last/232#.W70DLi8ZPow</a>

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Media Capacity	How to get the attention of Media and maintain engagement		Generations and advocacy: What approach works best?  How to prepare for media interviews at your next charity fundraising event  Spreading the word: 8 ways to get media attention for your nonprofit's positive news	<a href="https://charityvillage.com/cms/content/topic/generations_and_advocacy_what_approach_works_best/last/142#.W700Fy8ZOCQ">https://charityvillage.com/cms/content/topic/generations_and_advocacy_what_approach_works_best/last/142#.W700Fy8ZOCQ</a>  <a href="https://charityvillage.com/cms/content/topic/how_to_prepare_for_media_interviews_at_your_next_charity_fundraising_event/last/142#.W700oC8ZOCQ">https://charityvillage.com/cms/content/topic/how_to_prepare_for_media_interviews_at_your_next_charity_fundraising_event/last/142#.W700oC8ZOCQ</a>  <a href="https://charityvillage.com/cms/content/topic/spreading_the_word_8_ways_to_get_media_attention_for_your_nonprofit_s_positive_news/last/142#.W70Qry8ZOCQ">https://charityvillage.com/cms/content/topic/spreading_the_word_8_ways_to_get_media_attention_for_your_nonprofit_s_positive_news/last/142#.W70Qry8ZOCQ</a>