

Development of a National AYA Professional Organization (CM2.0)

Summary of
AYA National Stakeholders Meeting
December 13, 2019, DFW

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In attendance:

- Karen Albritton
- Amy Ash (FWAYA scribe)
- Amelia Baffa
- Fayruz Benyousef (facilitator)
- Smita Bhatia (phone)
- Archie Bleyer (phone)
- Hal Crosswell
- Simon Davies
- Jaime Estrada
- Karen Fasciano
- Brandon Hayes-Lattin
- Becky Johnson
- John Letterio
- Lauren Lux
- Susan Parsons
- John Perentesis
- Damon Reed
- Michael Roth
- Stu Siegel
- Dan Stroud
- Brock Ulman (phone)
- Ashley Wilder-Smith (phone)
- Brad Zebrack

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There was universal consensus to build a national AYA organization.

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What will its mission be?

- Previous mission of Critical Mass was to increase survival rates and QOL for AYAs
- Mission of CM2.0 will be focused on **decreasing the costs and losses resulting from an AYA cancer diagnosis.** It will do this through engaging, connecting, educating, organizing and supporting AYA professionals committed to that mission.

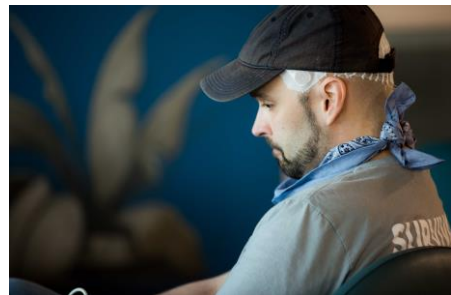
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What will be the structure? Will there be members?

- It will be membership organization, with dues.
- Initially members will be individual AYA professionals, with benefits being discount to meeting, other educational offerings.
- In the future, we will consider offering memberships to organizations when we have developed resources that would create value to an organization rather than an individual- might include JAYAO subscription, group discounts to annual meeting, program building tools
- It will be a nonprofit (501c3), supported by a combo of philanthropy, member dues (individual, but more hefty organization), grants
- Much work to be done detailing out org structure
- Unresolved –whether individual AYA survivors/advocates (no-professionals) would be members per se (versus advisory)

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Breakout Groups – Should the National Organization address the following areas?



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Education and Awareness

- NO:
 - AYAs directly (although maybe if we make a resource that can be provided to programs to give to patients this would be a perk to membership- ala COG parent handbook)
 - General Public Awareness
- YES:
 - Health Professionals (high priority) – how to care for AYA, how to build a program
 - Via: JAYAO, newsletters; chat groups; annual meeting (network of regional meetings), trainings, , learning community
 - This would be main benefit of membership- not all public access
 - Not just physician education – also nursing, SW, psychology, CLS, etc.
 - Awareness to non-oncology providers
 - Health Systems
 - Via: Standards, process improvement toolkits
- MAYBE/ LATER:
 - Insurance/Payers
 - Pharma
 - Legislators and Health Decision Makers (lobbying)

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Advocacy/ Policy

- No legislative agenda but maybe later
- Would like to be considered a stakeholder and resource for data, opinion, support for those seeking to influence
- Continue work with NCI to tell stories about military seeking funding for AYA grants
- Advocate for specialized AYA professional training

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Research



- Organization will not do any clinical therapeutic research
- Will not be applying for grants or putting out RFA/funding grants
- May “facilitate” research or do QI projects, especially in Cancer Care Delivery. Examples:
 - Advocate for availability of/access to trials
 - defining and evaluating delivery of high-quality care
 - Financial toxicity
 - Coordination of databases/registries
 - Develop consensus and provide expertise on research priorities/agenda
 - Keep catalog of ongoing research and researchers

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Patient Support

- Organization will not provide direct patient care
- General consensus org will not be a direct resource for patients either
 - Partner with current orgs who already interact with patients
 - Question of whether we will be keeper of “Mission Control” which is compendium of AYA resources for patients, currently managed by Ulman Foundation- takes time and money locally and accuracy depends on info being updated by entities (could we
 - Question of whether we will take on patient educational material- not disease specific as much as How to advocate for themselves, what questions to ask
- Focus on enabling providers and service providers
- Would like to engage patients in the organization via an advisory board

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Standards

- YES! This would be one of roles of the organization-
- Need to flush out interplay with NCCN; probably help with defining standards but then take next step and focus more on facilitating implementation, providing metrics/tools and monitoring, and studying the impact of following standards (adherence, ER visits, readmittance, sepsis, ICU stays, survival, QOL, economic savings) on AYA programs and institutions
- Need these outcomes to give ROI to philanthropists and anyone who supports us
- Do not favor being a certifying body (especially initially- would not have credibility, etc)

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Position Statements

- Yes! This probably falls under standards and education much of time
- There will be times where appropriate for a statement to come from this org (because we have the data and the “gravitas” to
 - Enable providers to have backing of national org when trying to implement change
 - Advocacy/legislative work



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COMMITTEES

- EARLY:
 - Organizational structure –tasked with drafting overall structure – both initial and proposed final, determining skillsets and manpower hours needed; explore legal issues (nonprofit status; whether to use another org as umbrella first)
 - Finance and Development: explore opportunities from individuals, foundations, sponsor, grants, etc. Develop business plan
- NEXT:
 - Annual Conference- If we decide to have one early 2021- may expand Texas AYA Conference (slated to be in Houston that year)
 - Member Services- Start with individual membership- develop criteria, pricing, benefits
- LATER:
 - Patient Advisory Council
 - Standards & Measures
 - Professional education
 - Annual conference
 - Program Development
 - Study Impact
 - Financial Stability

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One year from now...

- Develop & Populate 4 Committees- Structure/Planning, Finance/Fundraising, Annual meeting and Membership
- Work on establishing 501(c)3, BOD
- Focus on defining our mission, vision, definitions and key priorities- think of early focus that is big problem, will meet patient need, be obtainable (early small win), appeal to funders
- Have part-time admin to organize, lead communication (take minutes, distribute)
- Merge with/incorporate SAYAO and JAYAO
- First Annual Meeting of AYA professionals (early spring 2021??)
- {{Develop an AYA Mentoring Initiative}}- this was an idea thrown out- not sure it reached consensus as a priority in year 1, but prob. need to have some project/deliverable other than annual meeting

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National AYA Organization Stage 1 (6 months)

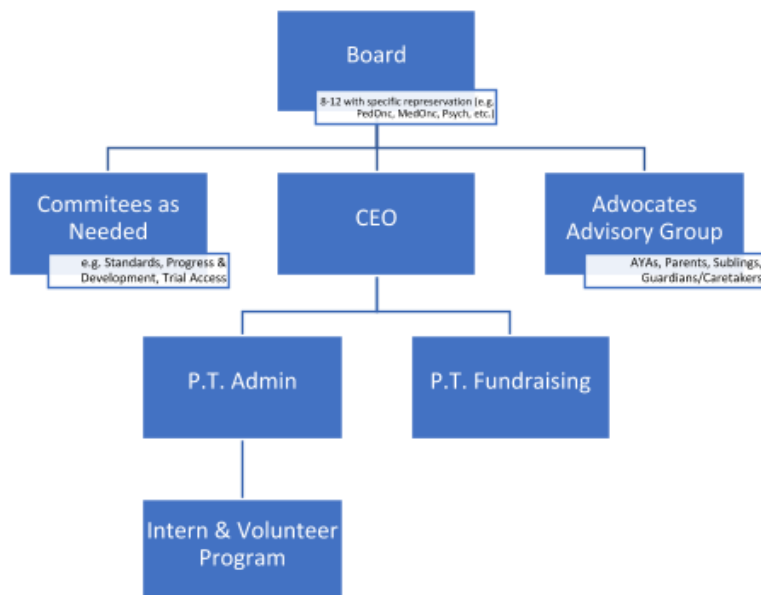
Decide Legal Structure
 Initiate 2 yr Funding Plan
 Decide on Organization Structure
 Decide on Key External Relationships
 E.g. COG, SWOG, NCCN, etc.
 Establish Board
 Recruit CEO?



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National AYA Organization Stage 2 (2 years)

Establish Organization
 Establish Communications with AYA Community
 Develop Fundraising Plan
 Develop 3-5 Year Strategy
 Establish Key External Relationships
 Annual Meeting



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