

# **Survey on ADCs- Alzheimer Association Relationships**





# Conclusions

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- **Response rate: 100% (30/30)**
- In general: good relationship
- The relationship needs constant nurturing



# General Questions

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	<u>YES</u>	<u>NO</u>	<u>N/A</u>
■ ADC currently working with local chapter?	28	2	-
■ ADC referred patients to chapter in the last 6 months	27	1	2
■ The chapter referred to the ADC in the last 6 months	25	2	3
■ Joint activities in the last 6 months:	30	-	-
■ Exchange of information	Often: 23	Sometimes: 7	



# General Questions

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Rank the collaboration with the local chapter (from 3: highest to 0)

	<u>3</u>	<u>2</u>	<u>1</u>	<u>0</u>	<u>NA</u>
Educ sessions for families	18	8	2	2	
Referral for services	16*	10	3	1	
Minority Outreach:	13*	8	4*	4	2
Educ sessions for providers	10	12	5	2	1
Clinical Trial Recruitment	6	10	10	4	
Educ sessions for physicians	4	14	7	5	

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- In general: goodwill and good relationships
- Poorest response: clinical trials referrals



# Genetics Initiative

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- Is your ADC currently working with the local chapter on the Genetics Initiative? YES: 15/30
- Did you get families referrals from the local chapter in the last 6 months? YES: 5/30 NA: 4
- How many?: Not sure-unknown
- Did you jointly organize activities to publicize the genetic initiative in the last 6 months: YES: 14/30 NA: 1



# COMMENTS

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## Perceived Barriers



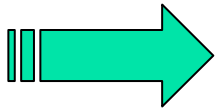
# Alzheimer Association

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Recent Alzheimer Assoc reorganization of chapters:



some confusion



change in connectivity



# ADCs

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- Competing demands
- Multiple allegiance
- Communication





# Insufficient dialogue

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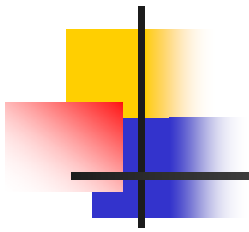
- Insufficient communication between the 2 groups
- Unreliable flow of information
- Unclear message (research vs service)
- Perception of lack of interest
- Territoriality
- ? Distrust



# Organizational issues

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- Need better listserve
- Need more informational website
- No tracking of patients



# SUGGESTIONS



# Suggestions for the Alzheimer Association

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- Improve communication when there are several chapters serving one ADC catchment area and more than one ADC serves one chapter
- The national Alzheimer Association should encourage these collaborations more directly
- Track requests
- Give feedback
- Highlight ADC clinical trials in the Alzheimer Association directory



# Suggestions for the ADCs

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- Work on barriers for referral - real and perceived examples: delay before initial visit- not everybody is suitable - ADCs viewed as competitors
- Give feedback
- Meet with the local chapter person
- Change perception of “research” versus “service”
- Educate local directors of Chapters and program developers about AD (be a local information source)
- ADRC faculty offering service and education will encourage enrollment
- Need more joint planning initiatives for the community



# For the Genetics Initiative

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- NEED more sharing of information
- Make sure the ADC and local chapter contacts are known and know each other
- Do joint news release and media blitz
- Chapters should receive updated material and information from the ADC
- Need meetings with the chapters specifically about the genetics initiative
- Involve the Administrators (IRB - HIPAA)



# Discussion

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- Should we have a joint listserve ADC-Chapters?
- How can we better track referrals?
- How can we optimize feedback?
- How useful are the support groups as an information/referral medium and otherwise?

