

Genetic Contributions to the Developmental Journey


Part II

A conversation with the NYMAC Genetics Team and Virginia Genetic Navigators




Logos for NYMAC, VEPD, VCU, and other partners are at the bottom.

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Radhika Sawh Alissa Terry Dana Yarbrough Lisa Richard



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AGENDA


Part 1

- Genetics 101 review
- Why does genetics matter for EI?
- "Red Flags" for genetics in children

Part 2


- Who is NYMAC and what do we do in VA?
- Who are the Virginia Genetic Navigators (GNS) and what do they do?
- How can NYMAC and VA's GNS be a resource for EI professionals?

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Pre-Webinar Survey

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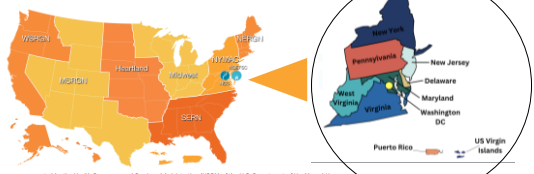
Pre-Webinar Survey



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Who is NYMAC?

- One of seven **Regional Genetics Networks (RGNs)** supported by federal grant funding from **The Health Resources and Services Administration (HRSA)**
- The NYMAC region includes 10 diverse jurisdictions and 62 million people.



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NYMAC collaborates with local stakeholders to promote **INCREASED ACCESS TO GENETICS SERVICES**


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How Does NYMAC Achieve Its Goal?



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How Does NYMAC Achieve Its Goal?



Improve the genetics delivery system through collaboration with diverse stakeholders

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How Does NYMAC Achieve Its Goal?



Telemedicine projects to make genetics appointments easier for families

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How Does NYMAC Achieve Its Goal?



Education about genetics to families and professionals

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NYMAC Teams

- Individual teams of diverse stakeholders were created for each of our 10 jurisdictions
- The goals of each team is to
 - assess the needs and barriers specific to that jurisdiction
 - implement NYMAC funded projects to improve access to genetic services



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NYMAC Team VA: A Collaborative Effort

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SARAH CANNON
Virginia Cancer Support

VDH VIRGINIA DEPARTMENT OF HEALTH

VIRGINIA NEWBORN
INCREASING PREVALENCE

EHD1
VIRGINIA

NYMAC Team VA:
A Collaborative Effort

CARE CONNECTION FOR CHILDREN

VCU

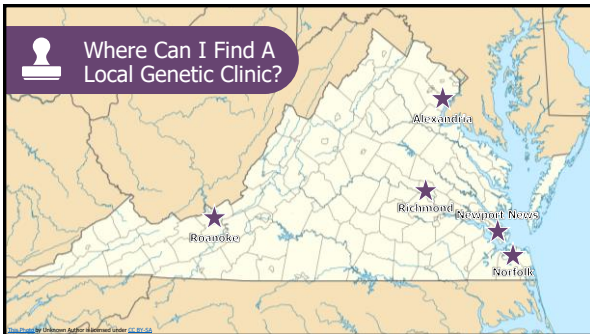
Children's Hospital of The King's Daughters

UNIVERSITY OF VIRGINIA

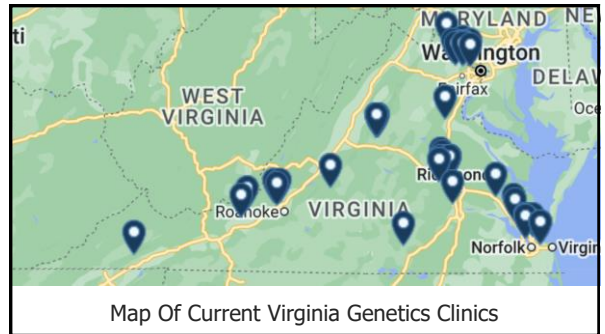
Pediatric Specialists of Virginia

Children's National INOVA

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What barriers prevent Virginia families from accessing genetic services?

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NYMAC Projects from Across our Region

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NYMAC Projects from Across our Region

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Our Focus In Virginia: Supporting Families Who Require Genetic Services

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NYMAC partnered with the Center for Family Involvement (CFI) @ VCU

**1 ON 1
SUPPORT
ALWAYS
FREE**

**GENETIC
NAVIGATOR
PROGRAM
OF VIRGINIA**

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The Center for Family Involvement (CFI) works with families to increase their skills as advocates, mentors, and leaders so that families, children, and young adults with disabilities can lead the lives they want.

For more information:

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Dana Yarbrough
CFI Director
dyarbrough@vcu.edu

Nickie Brandenburger
F2F Director & CFI Co-Director
nbrandenb@vcu.edu

Cheryl Bishop
Office Coordinator
cbishop@vcu.edu

Renie Soniat
Co-Director of the Family to Family Network of Virginia
rsoniat@vcu.edu

See handout for more info!

F2F Team	F2F Team/Specialists	Cultural Brokers	Disability Specialists
<p>Blue Ridge F2F Hub Rebecca Sticker rsticker@vcu.edu</p> <p>Central Virginia F2F Hub Heidi Smith hsmith@vcu.edu</p> <p>Hampton Roads F2F Hub Doreen Reid dreid@vcu.edu</p> <p>Northern Virginia F2F Hub Jan Rosen jrosen@vcu.edu</p>	<p>Southwest Virginia F2F Hub Lisa Howard lhoward@vcu.edu</p> <p>Tidewater F2F Hub Joan Burnett jburnett@vcu.edu</p> <p>Elderhood Specialist Norma Cooper ncooper@vcu.edu</p> <p>Rural Specialist Lisa Howard lhoward@vcu.edu</p>	<p>Arabic Cultural Broker Amal Zogbi azogbi@vcu.edu</p> <p>African American Cultural Broker Maureen Copeland mcpeland@vcu.edu</p> <p>Hispanic/Latino Cultural Brokers Edgar Garcia egarcia@vcu.edu</p>	<p>Diversity Fellow Jill Peng jpeng@vcu.edu</p> <p>Visita Impaired/DB Specialist Deann Pether Snow dpether@vcu.edu</p> <p>Deaf/Hard of Hearing Specialist Doreen Schmidt dschmidt@vcu.edu</p> <p>Mental Health Specialist Patricia Brown pbrown@vcu.edu</p>

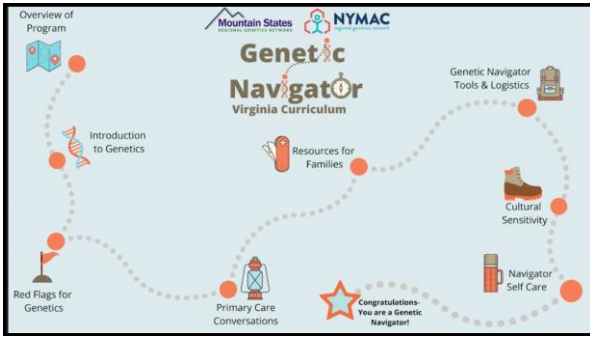
(877) 567-3122 | cfipartnership@vcu.edu | www.centerforfamilyinvolvement.org | (877) 567-3122

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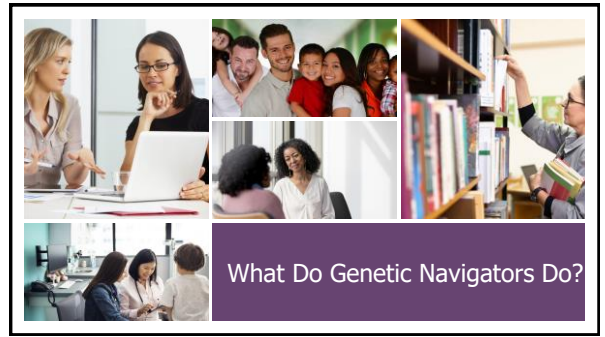
CFI Model of Family Support

Intentional matching of a parent with a newly diagnosed child with disabilities with a 'seasoned', trained parent for emotional, informational, and systems navigational support

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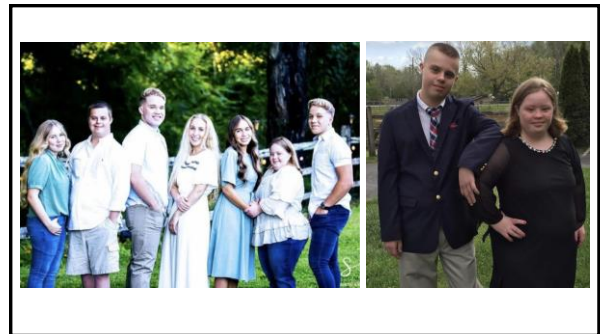
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A handout titled "DISCOVER THE VIRGINIA GENETIC NAVIGATOR PROGRAM" with the NYMAC logo. It includes a "See handout for more info!" button and several sections of text:

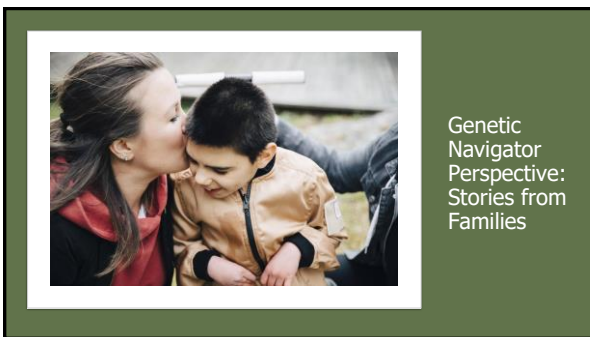
- What is it?** The program aims to help families of children or adults with identified or suspected health care needs more easily access and navigate genetic services.
- Who are genetic navigators?** Genetic navigators are parents of children with genetic diagnoses who have their own personal experiences using genetic services.
- How much does it cost?** The program is FREE of charge.
- How can genetic navigators help?** They are prepared to simplify the genetics journey by providing one-on-one support to families, offering genetic testing or self-referral for an appointment with a genetic counselor or geneticist.
- Who created this program?** The program is a joint effort between the Virginia Department of Health, the Center for Family Assessment at OSU, and the NYMAC Regional Genetics Network.
- How are genetic navigators trained?** Genetic navigators complete eight training modules (which can add to their own prior skills) on their medical journey.

 At the bottom, it says "Find local genetic resources and genetic advice in VA at nymacgenetics.org/va" and "Request our course" with a QR code.

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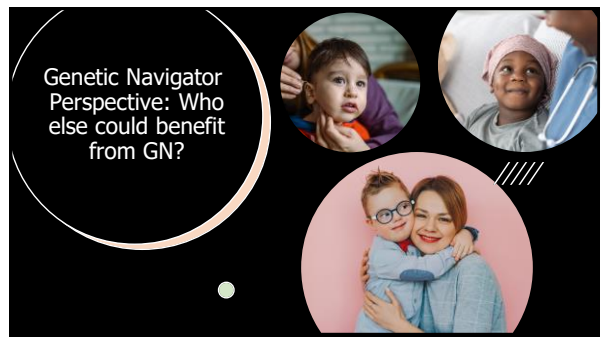


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Genetic Navigator Perspective: Stories from Families

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Perspective from Genetic Counselors (GCs)

Virginia GCs in a study all agreed that a genetic navigator program is a great idea. They specifically thought Genetic Navigators were:

- beneficial for culturally and geographically underserved communities
- beneficial for families whose healthcare providers may not have a great understanding of when to refer to genetics

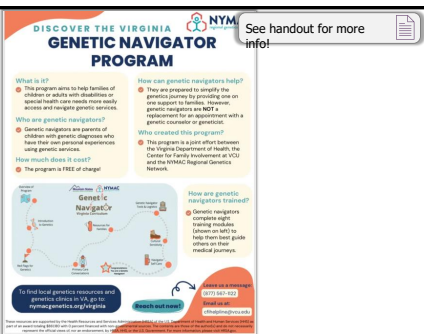


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"...A mom talking to another mom or dad talking to another dad can make connections, build rapport that we as professionals don't have that same kind of shared life experience to really connect on that level."

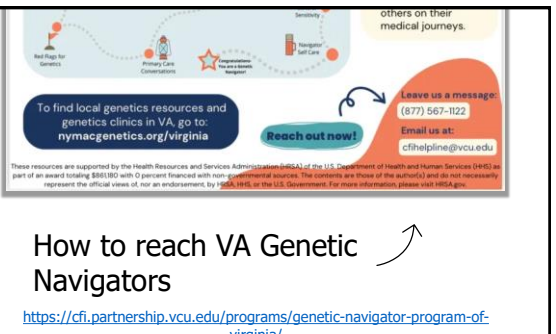
-GC Participant

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See handout for more info!

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To find local genetics resources and genetics clinics in VA, go to: nymagenetics.org/virginia

Reach out now!

Leave us a message: (877) 567-1122

Email us at: cfihelpline@vcu.edu

<https://cfi.partnership.vcu.edu/programs/genetic-navigator-program-of-virginia/>

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What does this have to do with Early Intervention?



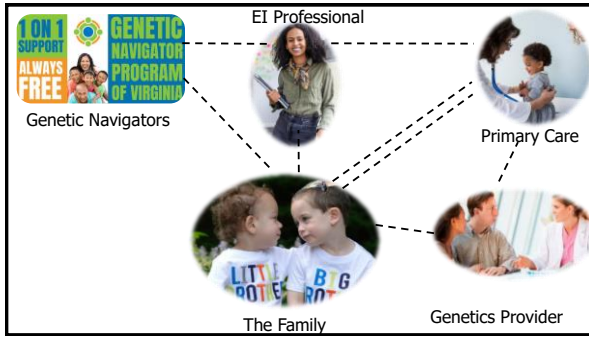
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EI Professionals are great:

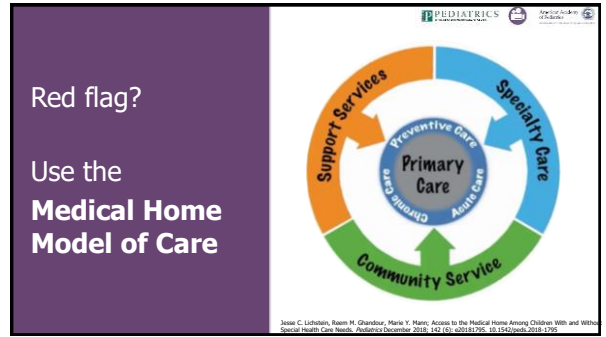
Detectors Connectors



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EI professionals and GNs can help Empower the family to talk to their PCP

- Remind parents: "You are the expert on your family"
- The provider may have the scientific knowledge but the family has the personal history and day to day experiences
- Teach the family tools to advocate.

The slide includes a silhouette of a person standing with arms raised, holding a large, glowing lightbulb. At the bottom, it says 'CREDIT: NYMAC Virginia Genetic Navigator Training'.

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Tips for Families About Conversing with Their PCP About Genetics Concerns

- Prioritize top 3 concerns
- Record your observations about your concerns and bring them
- Bringing a **trusted** person with you to the appointment
- Schedule a follow-up appointment if there is not time to address all of your concerns
- Speak in your native language & ask for an interpreter to help you explain your concerns

CREDIT: NYMAC Virginia Genetic Navigator Training

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Conversation starters for families to start about genetics with their PCP... [See handout for more info!](#)

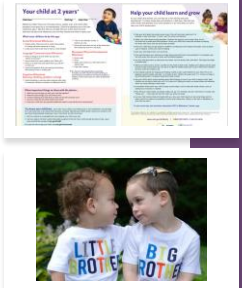
- I am concerned about...
- My concern of _____ from our last visit has not resolved (worsened). What can be done to explore further?
- In talking with my family, I learned we have a history of _____. Is it possible _____ is genetic?

CREDIT: NYMAC Virginia Genetic Navigator Training

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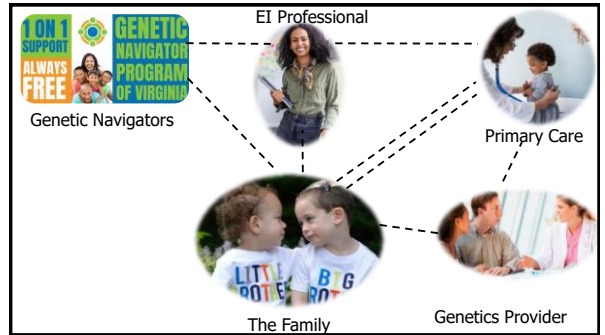
EIs, GNs, and Genetics in Action:
A CASE EXAMPLE:

- 2 year old receiving Speech Therapy
- Over time, the therapist notices other concerning behaviors and symptoms
- She also begins to notice that the boy's younger brother also has some significant delays



<https://fragilex.org/newsroom/casestudy/the-garber-family-story>


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There is no cure, but the genetic diagnosis can help the family:

- Know what to expect in the future
- Guide best therapies, interventions, and medications to treat symptoms
- Plan for health risks for other children and other family members such as primary ovarian insufficiency, tremor/ataxia, and mental health issues.
- Connect with other families and clinical trials



<https://fragilex.org>

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EI Professionals are great:

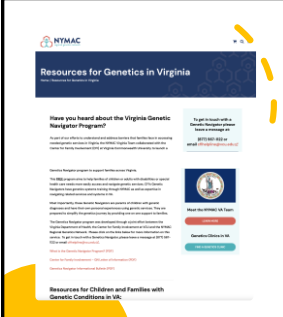
Detectors



Connectors



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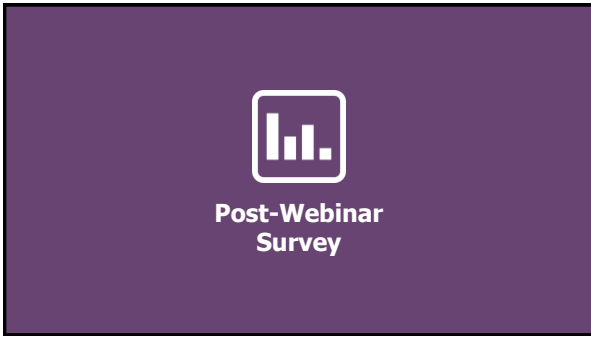
For more information about the Virginia Genetic Navigator program, please visit the NYMAC Team Virginia webpage at:
<https://nymacgenetics.org/virginia/>

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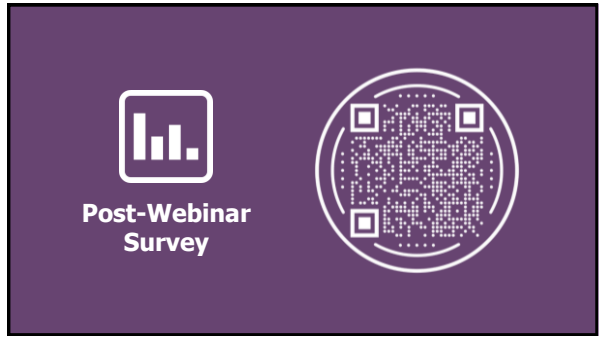
Thank you!
Questions?

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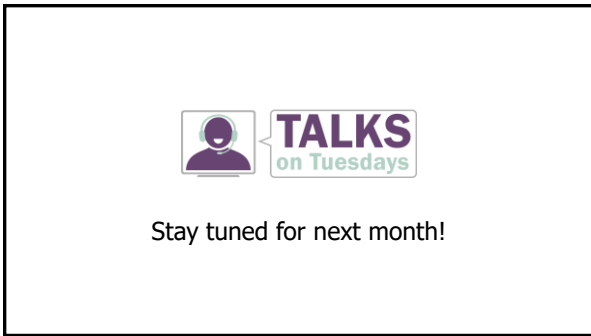
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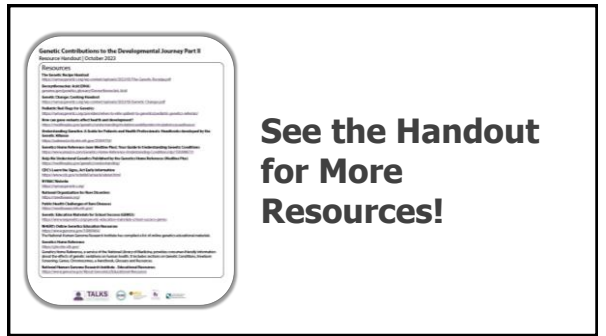
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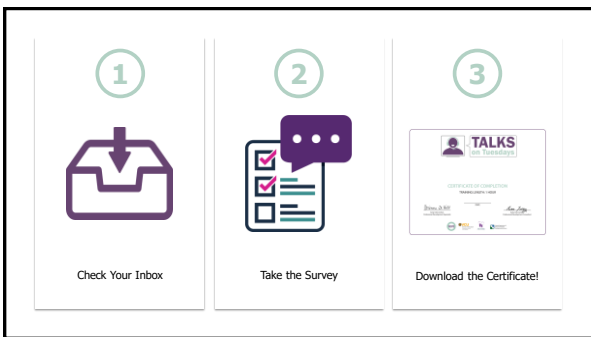
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